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ABSTRACT

The purpose of this Congressional study is to underscore the continuing contribution of the family in providing care to the frail and disabled elderly. This study has been developed to distill information that currently exists, to provide new data based on national estimates and to highlight both public and private sector initiatives targeted at caregiving. Informal caregiving is the first topic discussed. An historical perspective is provided, as well as current demographic, health, and social trends. Next characteristics of the caregivers themselves are described, including their gender, age, marital status, employment, economic status, health status, and living arrangements. The benefits and negative aspects of caregiving are described, including sources of stress and types of caregiver strain. The public sector response to informal caregiving is discussed. These topics are covered: status of current public policies; public sector support for informal caregivers, including service and financial strategies; and federal legislation, including the Older Americans Act Amendments of 1984 and the Respite Care Act of 1986. The private sector response is also described, including education and training, respite care, and employee benefit programs. The report concludes that family members, friends and neighbors have continued their long tradition as the principal source of long-term care assistance to impaired elderly persons, and these caregivers will continue to be essential in providing care to dependent elderly. (ABL)

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[COMMITTEE PRINT]

EXPLODING THE MYTHS: CAREGIVING IN AMERICA

A STUDY

BY THE

SUBCOMMITTEE ON HUMAN SERVICES

OF THE

SELECT COMMITTEE ON AGING
HOUSE OF REPRESENTATIVES

SECOND SESSION

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FOREWORD

In the past few years, there has been much discussion about the need to return to family values and to increase familial responsibility in the care of frail and disabled family members. What has been greatly misunderstood is the extent to which families have been and continue to be involved in the care of the dependent elderly.

Recently, interest has been directed to that group of individuals known as family caregivers. They are generally daughters and wives, but also husbands and sons who, in addition to a variety of other activities, are responsible for the care of dependent family members. Indeed, family caregivers provide between 80 and 90 percent of the medically related care, personal care, household maintenance, transportation and shopping needed by older persons. Thus, far from abrogating their responsibility, family caregivers provide care for dependent family members, often at a great emotional and financial cost.

In recognition of the ongoing contribution of the family caregiver, the President signed legislation introduced by Congresswoman Olympia Snowe and Senator John Glenn designating the week of November 24 through November 30, 1986 as "National Family Caregivers Week." For the first time, we as a nation can include in our celebration of Thanksgiving a special note of appreciation for the vital role of the family caregiver.

This week serves, however, as more than a symbolic gesture to family caregivers. Indeed, "National Family Caregivers Week" represents an important educational thrust designed to dispel the false notion that the family is no longer involved in the care of elderly family members.

This print was conceptualized by Congresswoman Snowe as a means of educating us all to the importance of caregiving. Family and nonfamily caregivers create an informal network of care that is crucial in ensuring that aged individuals remain in the community as long as possible. This print is a tribute to informal caregivers everywhere.

Mario Biaggi, Chairman
Olympia Snowe, Ranking Minority Member

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"The independence of family (caregiving) patterns from public policy is more impressive than the connections. While the demise of filial relations and responsibility has regularly been reported and their survival regularly rediscovered, parents and children have conducted their affairs with each other without attention to either kind of news. . . Family life flows on, untroubled by scholars and columnists" (Schorr, 1980: 41).

I. INTRODUCTION

The United States, like all western countries, is facing an unprecedented growth in its elderly population. In the last two decades, the older population has grown twice as fast as all other age groups. Improvements in health care and technology and changes in lifestyle have merged to assure that more elderly reach old age and that they are in better health than in any previous period in history. Not only is the population as a whole growing older, but the older population is itself aging. For example, the 85 and older age group is expected to be seven times its current size by the middle of the next century.

In addition to shifts in the demographics of the population, there have been changes in access to the health care system. Beginning in 1983, efforts to contain the rapidly burgeoning cost of hospital care led to the development of a prospective payment system for Medicare hospital beneficiaries. The change from a retrospective cost-reimbursed system to one in which reimbursement is based on fixed payment rates provided in advance of the provision of services has altered the incentives for hospitals. As a result, hospitals will make a profit when they provide care which costs less than the prepaid amount; those which keep patients longer will lose money. The outcome of this policy has been a decrease in the number of days of hospitalization. Patients have been released "quicker" into the community. While this is not intrinsically harmful to the individual, it has meant a greater pressure on the family and the community to provide care.

This increased demand for community-based care

has occurred at a time when informal and formal systems of care are coming under greater pressure. The change in the structure of the family has been widely documented. For example, many women must work while at the same time addressing the needs of frail and dependent older family members, providing care for children, and meeting other household demands. In addition, the increased divorce rate has led to disruptions which have altered the ability of the family to provide care. Furthermore, geographic dispersion has made it more difficult for families to provide the kinds of assistance needed by frail and impaired elders. Finally, with increased life expectancy there is a greater tendency for older individuals to care for elderly spouses, and perhaps even older parents.

Recent efforts to deal with the national deficit have led to a curtailment of formal care services. For example, as a result of efforts to slow the growth of the Medicare home health benefit, denial rates have increased at the same time that more older persons are in need of care. Cost containment is an underlying factor which is coupled with the fundamental concern that the care provided by families not be supplanted by services provided through federally financed formal care programs.

Contradictory trends have developed with respect to the need for and the ability to provide care by the family. On the one hand, as a consequence of the growing number of older persons and the growth among the so-called "old-old," there are more older persons who require varying levels of health care and social services. On the other hand, families are under greater stress to provide these services as they try to deal with competing demands and the increasing unavailability of services that can complement their care to family members in need.

The purpose of this report is to underscore the continuing contribution of the family in providing care to the frail and disabled elderly. This print has been developed to distill information that currently exists, to provide new data based on national estimates and to highlight both public and private sector initiatives targeted at caregiving. The national data discussed in this print are drawn from the Informal Caregivers Survey, a component of the larger 1982 Long-Term Care Survey conducted by the Department of Health and Human Services to study disabled elderly persons living in the community.

II. INFORMAL CAREGIVING: HISTORICAL AND CURRENT PERSPECTIVES

Overview

Informal caregiving refers to unpaid care provided to an elderly person who has some degree of physical, mental, emotional or economic impairment which limits independence and necessitates ongoing assistance (Horowitz, 1985). The Informal Caregivers Survey, from which much of the data in this print is drawn, focuses on two million caregivers aged 14 years or older who provide unpaid assistance to approximately one and a half million impaired elderly persons needing help with one or more of the activities of daily living (ADL). ADLs are measures of ability to perform daily tasks such as eating, bathing, dressing, getting in and out of bed/chair, toileting, and inside mobility. The level of disability of an elderly person is measured by the degree to which he or she requires assistance in performing one or more of these activities. The severity of impairment increases with the number of ADL limitations. Thus, this is an important subgroup of caregivers because they provide assistance to the most disabled elderly who are able to remain in the community primarily because of the care they receive.

Historical Perspective on Family Caregiving

In the face of considerable evidence to the contrary, the myth of family alienation and abandonment continues to persist. While the family has maintained an ongoing presence in caring for the aged, the 1980's has witnessed a resurgence of interest in familial responsibility for the care of the aged. Underlying this interest is the concern that family caregiving is on the decline in the United States. Many fear that publicly-sponsored programs will begin to supplant family care and that this expansion will add to the already exorbitant costs of long-term care for the elderly population.

This concern is not new. In fact, the question of familial responsibility for aged individuals has a long legacy in the history of America. While elderly persons always have chosen to remain independent as long as

possible, documents dating from the colonial period indicate that families were held responsible for those aged parents who could no longer care for themselves. An eighteenth century preacher expressed his concern when he warned that, "children that have been the charge of their parents to bring them up to be capable of doing something, should not presently, in hope of doing better for themselves, desert their helpless parents, as thinking it now time to look for themselves and left them shift as they can" (Haber, 1983).

In the colonial era, poor laws provided guidance regarding responsibility for indigent family members and established hierarchical lines of responsibility. By 1860, 18 states had enacted family expense laws which required that adult children provide financial support for their aging parents; by 1937, 37 states had included family responsibility laws in their state statutes. And even into the 1960's, legal family responsibility was a common feature of locally administered, means-tested, public assistance programs (Callahan et al., 1980). Nevertheless, beginning with the introduction of the Social Security Act in the 1930's, there was a shift in the responsibility from the family as the major source of support to a combination of public and private resources (Schorr, 1980).

Informal Caregiving Today

Today, the family remains as committed as ever to the care of dependent family members. Indeed, the majority of elderly persons, including those living alone, maintain close contact with their families. In 1984, four-fifths of aged persons who lived alone and who had children were in contact with a child in person or by telephone at least once a week. Furthermore, only 11 percent of the estimated eight million older Americans who lived alone had no living children or siblings. Even among this subgroup, 27 percent had recently seen a relative and 51 percent had visited with a friend or neighbor. In addition, 38 percent had talked on the telephone with a relative and 57 percent had had a telephone conversation with a friend or neighbor (Kovar, 1986).

Research indicates that the bulk of long-term care is provided by informal caregivers. Among aged persons with long-term care needs, only one in five are living in

nursing homes. The remainder continue to live in the community primarily because of the unpaid assistance of family, friends and neighbors. Furthermore, approximately three-quarters of noninstitutionalized disabled elderly persons rely solely on informal care. Only 5 percent receive all their care from paid sources (Liu et al., 1985).

Empirical evidence indicates that family care is one of the most critical factors in preventing or delaying nursing home utilization. For example, in a comparative study of matched samples of institutionalized and noninstitutionalized elderly persons with equivalent disabilities (Smyer, 1980), the single most important difference between the groups was the families' self-reported ability to care for their noninstitutionalized elders as long as necessary. Researchers (Colerick and George, 1986) examining predictors of the decision by caregivers to institutionalize elderly family members who suffer from Alzheimer's disease have underscored the importance of the caregiver context. "When physicians assess a patient's need for nursing home care, it is not enough to evaluate symptoms or to know how long the patient has been ill or functioning at the current cognitive level. The structure and characteristics of the caregiver support system are also important, and, in fact, are better predictors of institutional placement than are patient characteristics" (p. 497).

Studies have shown that widowhood, living alone and childlessness are significant predictors of institutionalization (Branch and Jette, 1982; Butler and Newacheck, 1981). In addition, elderly persons with family supports tend to enter nursing homes at much higher levels of impairment than do those without such informal care networks (Barney, 1977; Dunlop, 1980). This finding indicates that they are being maintained in the community longer.

The choice of caregiving tends to follow a hierarchical pattern. The primary caregiver is usually a spouse or an adult child, if the former is not available. In the absence of both, another relative (e.g., sibling, grandchild, niece or nephew) assumes the major responsibility for care. Finally, where no family members are available, frail elderly persons frequently turn to neighbors or friends for assistance (Arling and McAuley, 1983; Cantor, 1983).

While it has been postulated (Litwak, 1985) that the dependency needs of an older person are met effectively by a balance between formal services and informal supports, the data do not necessarily support this notion. In a recent analysis of data from the 1982 Long-Term Care Survey, Soldo and Manton (1985) found that extremely disabled elderly persons living with spouses used formal services only after they became incontinent and their condition warranted specialized medical attention. Among disabled older persons living with children, the use of formal providers was precipitated by the need for extensive supervision. These findings suggest that the use of the formal care system occurs only after care needs become more than the family and ancillary helpers can handle alone.

Research indicates that the majority of primary caregivers are female, either wives or adult daughters. In the case of the latter, there is little evidence that birth order or being the "most loved" child determines which sibling will assume the caregiver role. Rather, proximity to the elderly person and lack of competing demands appear to be the major factors in the decision to become the primary caregiver. Other persons in the caregiving network assume secondary roles; only infrequently does more than one caregiver share equal responsibility for the care of an elderly person.

Informal caregiving, and family care in particular, is motivated by at least three factors (Horowitz, 1985). The first is the love and affection felt toward the older person. Secondly, individuals are motivated by a sense of gratitude and the desire to reciprocate caregiving or other help that was provided by the elderly person at an earlier stage in the life cycle. Finally, many caregivers are motivated by an allegiance to a more generalized societal norm of spousal or filial responsibility. For caregiving daughters and sons, Brody (1985) suggests that having a dependent elderly parent has become a normative experience, one which may exceed the capacities of many families.

Caring for a disabled relative or friend has been compared with child care. In both instances, it has been assumed that females are the most suitable for the caregiver role. Elder care is unpaid labor which, like childrearing, often remains unseen. For many caregivers, these responsibilities demand the adoption of a lifestyle

which isolates the caregiver from the outside world (Graham, 1983).

While there is a tendency to draw analogies between child care and parental care, it is important to recognize the critical differences between them. In caring for a typical child, one can anticipate a gradual reduction in dependency as the youngster matures. On the other hand, caring for a frail elderly relative usually presages continued or increased dependency. One newspaper columnist recently wrote that "Our shame about aging prevents us from knowing and telling our children the dirty little secret of our human existence: When we too are old, we may need them — need to lean on them" (Goodman, 1985: A19).

Current Trends That Influence Family Caregiving

As previously noted, the question of familial responsibility for the care of the aged is not a new one for United States policy. But the convergence of several demographic, economic and social trends has precipitated increasing concern about the current and future status of family caregivers.

Demographic Trends

1. The Aging of the U.S. Population

Several demographic shifts have been occurring simultaneously in the U.S. population, including the aging of the general population, the aging of the older population, and the growing proportion of females among the elderly. These demographic shifts have had important implications for the changing American family.

With respect to the aging of the general population, in 1900, persons aged 65 and older represented just 4 percent of the U.S. population; in 1980, the 26 million elderly individuals represented 11 percent of the population, or one in every eight Americans. By the year 2000, persons aged 65 and older are expected to represent 13 percent of the population and by 2050 it is estimated that one in five Americans will be at least 65 years old (Chart 1-1, p. 13).

This growth in the elderly population has been most dramatic among those aged 85 years or older, the frailest segment of the population and those most likely to require extensive health and social services. The number of persons in this age category rose 165 percent between 1960 and 1980, and is expected to be seven times as large in 2050 as in 1980 (Chart 1-2, p. 14). Between 1984 and 2050, the population aged 85 years and over is expected to increase from 1 percent to over 5 percent of the total population and from 9 percent to 24 percent of the age 65 and over population (U.S. Senate, 1986).

Another important demographic trend is the disproportionate number of females in the elderly population. In 1984, for example, there were 17 million women and 11 million men aged 65 years and older. This disparity increases with age (Chart 1-3, p. 15). For example, among those 65 to 69 years old in 1984, there were 81 men for every 100 women. Among those 85 years and older, the gap widened to 40 men per 100 women (U.S. Senate, 1986). Because women, on the average, live longer than men, elderly women are more likely than their male peers to be living alone. Further, they are more likely to be economically disadvantaged and to experience multiple chronic health problems (Rix, 1984; Minkler and Stone, 1985). Consequently, elderly females are more likely to need assistance from children, other relatives, friends or neighbors.

2. The Changing Family Structure

The aging of the population has greatly affected the structure of the American family. In 1963, for example, one-quarter of people over the age of 45 had a surviving parent; by the early 1970's, one-quarter of people in their late fifties had a surviving mother or father (Murray, 1973). By 1980, 40 percent of people in their late fifties had at least one surviving parent, as did one-fifth of those in their early 60's, 10 percent of those in their late 60's, and 3 percent of those in their 70's (NRTA-AARP, 1981). In other words, one out of every ten people 65 years and older had a child at least 65 years of age (Atchley and Miller, 1980).

Declining fertility rates coupled with increased life expectancy have precipitated another demographic trend with important implications for caregivers. For the first

time in American history, the average married couple has more parents than children (Preston, 1984). Furthermore, women can expect to spend more years caring for an aging parent than for a dependent child. In 1900, for example, a woman spent 19 years with a child and only nine with a parent. Today, the average woman will spend 17 years of her adult life caring for a dependent child and 18 years helping her elderly parent.

Trends in the Health of the Elderly

1. Demand for Long-Term Care

The tremendous growth in the elderly population, and in the "over 85" group in particular, translates into an increase in the need for long-term care. Most older persons have at least one chronic condition and many have multiple conditions. National estimates (Liu et al., 1985) reveal that one-quarter of the aged are in need of some type of long-term care. Of this subpopulation, 1.4 million persons reside in nursing homes. The remainder, between 4.6 and 5.1 million elderly persons, depending upon the definition of disability used (Liu et al., 1985; Macken, 1986) are functionally impaired and living in the community. These individuals require assistance from another person with one or more activities of daily living (i.e., bathing, dressing, eating, transference in and out of bed/chair, mobility in one's living quarters, toileting) or with instrumental activities of daily living (e.g., shopping, cooking, housecleaning, laundry). Two-thirds of these individuals are moderately impaired with limitations in the instrumental activities only or in one or two activities of daily living. Approximately 850,000 elderly persons reside in the community with severe limitations (Liu et al., 1985).

2. Growing Cost of Institutional Care

The burgeoning of the aged population has been accompanied by an astronomical increase in the health care costs for older persons. In 1984, the 65 and over age group represented 12 percent of the population but accounted for approximately 31 percent of total personal health care expenditures. Between 1960 and 1982, the public share of these expenditures rose from between 28 to 55 percent, with the greatest growth attributed to nursing

home costs (U.S. Senate, 1985).

In 1960, nursing home expenditures were $480 million; by 1984 they had risen to $31.4 billion, an increase of 18 percent per year. Medicaid pays a large part of the nursing home bill; in 1970, for example, $1.1 billion or 59 percent of total Medicaid dollars for the elderly were spent on nursing home care (Fisher, 1980). By 1984, $10.4 billion or 68 percent of the Medicaid budget was expended on institutional care (Waldo and Lazerby, 1984).

3. Growing Cost of Noninstitutional Care

The escalating costs of health care for the elderly population, and the costs of institutional care in particular, have stimulated concern among policymakers about the capacity of families and other unpaid caregivers to maintain disabled elders in the community. As was noted earlier, families provide the bulk of long-term care services to their frail elderly relatives. Moreover, they do so with little support from public programs.

Given the limited public funding for these services, it is not surprising that almost three-quarters of all noninstitutional care (e.g., home health care, homemaker services, adult day care) is privately financed by the elderly and/or their relatives (Soldo, 1983; Liu et al., 1985). Among the 1.1 million impaired older persons who received home care in 1982, 41 percent paid for these services entirely out-of-pocket. With an average payment of $164 per month, researchers estimate that approximately $1 billion is spent out-of-pocket by disabled elderly persons each year.

Social Trends

1. Decreased Fertility

While today's disabled elderly population tends to rely primarily on family and friends for most of their long-term care needs, several social trends may alter the size and configuration of the future pool of informal caregivers. For example, fluctuations in fertility rates are projected to have a "seesaw effect" on the number of elders and their potential caregivers. The unusually low birth rate which prevailed during the Depression era has created a situation in which there are many more elders

than there are offspring (Clinksdale et al., 1985). However, as the parents of the baby boom generation age, the pool of offspring available to care for parents aged 65 to 79 is likely to expand. In contrast, the decreasing ratio of elderly persons aged 80 and older to adult children is expected to continue to widen and peak in the year 2000, decline for 20 years and then reach its zenith in 2030 (Doty, 1986).

2. Increased Divorce Rate

The steady increase in the rate of divorce over the past thirty years (Masnick and Bane, 1980) also has implications for the future pool of caregivers. Those divorced older persons who fail to remarry will be without spousal support. In fact, due to the combination of extended female longevity patterns and the escalating divorce rate among older persons, the number of single elderly females is expected to increase 25 percent by the year 2000. The responsibility for the care of these women will rest primarily with their children, other relatives, friends or neighbors.

It may be difficult for children of divorced parents to provide the care needed because of family conflicts and/or the logistics of caring for two persons who do not live together. On the other hand, Mutschler (1985) has noted that remarriage of the parent could increase the potential pool of family members (e.g., stepchildren) available to provide care. This assumes that the relationship between stepchild and stepparent is an amicable one and that the stepchild is available to assume elder care obligations.

Findings from a recent study (Cicirelli, 1983) also suggest that marital disruption among caregiving children due to divorce, separation, or widowhood is associated with fewer types of care being provided by offspring to their elderly parents. In addition, caregiving children with marital disruptions tend to express a weaker sense of filial obligation than those with intact marriages.

3. Increased Labor Force Participation

Many experts are concerned that the increasing labor force participation rate among women may reduce the size of the caregiver pool in the future. Currently, 51

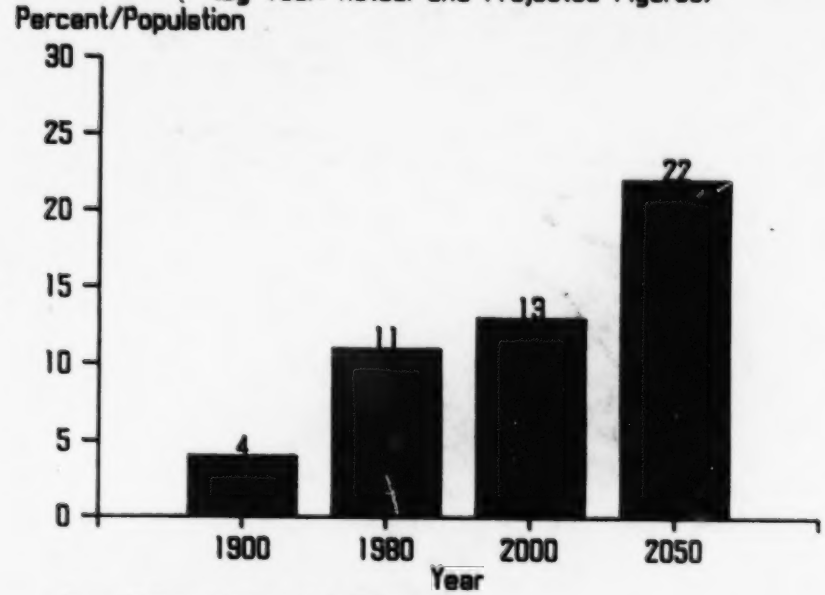
percent of adult women work outside the home and three-quarters of them work full-time. Moreover, 62 percent of women aged 45 to 54 and 42 percent of those aged 55 to 64 are gainfully employed (U.S. Department of Labor, 1984). This group of middle-aged females is composed, in large part, of adult daughters and daughters-in-law who are most likely to assume the major responsibility for the care of a disabled parent or husband. As more women enter the labor market, the ability of families to provide the type and level of care needed by the frail aged may be affected. One potential outcome would be a shrinking of the pool of informal caregivers. On the other hand, this trend could encourage more adult sons to take responsibility for the care of a frail and/or disabled parent.

Caregiving responsibilities, alternatively, may have an effect on labor force participation. For example, women may choose part-time work, accept jobs with less demanding work schedules or less travel, or decide to turn down a job or promotion because of the demands of caregiving.

Chart I-1

Percent of the Population Aged 65 and Over

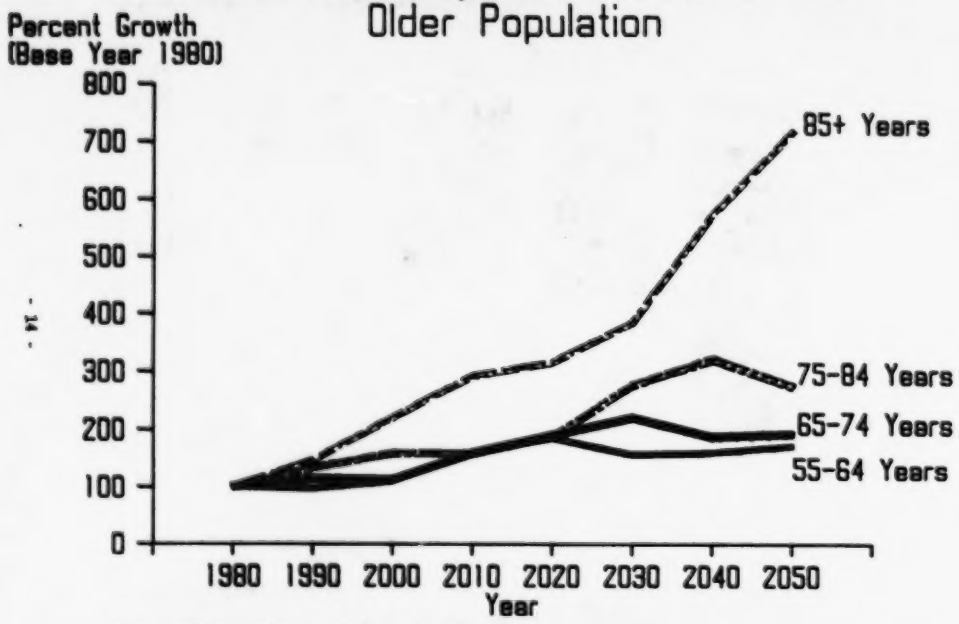
(By Year: Actual and Projected Figures)



Source: U.S. Bureau of the Census, Current Population Reports Series P-25, No. 000 and Census of the Population, 1900

Chart 1-2

Actual and Projected Growth of the Older Population

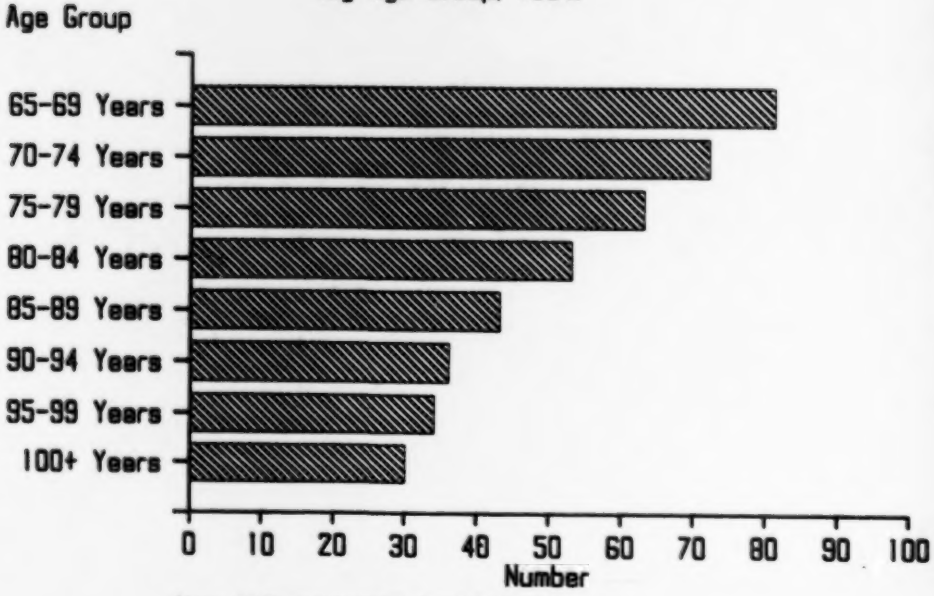


Source: U.S. Bureau of the Census, Current Population Reports
Series P-25, No. 952

Chart 1-8

Number of Men Per 100 Women

(By Age Group, 1984)



Source: U.S. Bureau of the Census, Current Population Reports, Series P-23, No. 152

- Mrs. G., 62, found herself torn between two telephone calls. In one she heard about her 83 year old father who had fallen and was feeling sick. In the other, she heard her daughter's tired, sad voice pleading for her presence because her two small children were sick.

- Delores, a San Francisco trial lawyer and Jackie, a school teacher, are two unmarried sisters who live with and share responsibility for their 79 year old widowed mother who is blind and paralyzed by a stroke.

- Last year, Lucy B., 67, took a leave of absence from her job to care for her terminally ill husband, who died shortly thereafter. A month later, her severely impaired 88 year old mother moved in, and Lucy has never returned to work.

- Mrs. T. cares for her 78 year old father, a stroke victim, in her home; she finds this caregiving relatively free of stress. She has four live-in helpers — her husband, two teenage daughters and her mother. Two sisters and a brother live nearby and also share the responsibilities.

- Mr. M., an 86 year old retiree, killed his wife of 55 years and then committed suicide. He had been caring for his spouse since she was stricken with Alzheimer's disease five years before and apparently could no longer cope with the pressure.

Introduction

The cases above underscore the heterogeneity of informal caregivers providing unpaid assistance to elderly relatives and friends. There are distinctions among family caregivers and there are important differences between family caregivers and the larger population. In general, however, caregivers tend to be female, about 57 years of

age, and live in the same household as the care recipient. When compared to the total population of caregivers and non-caregivers, caregivers are less likely to be employed, are more likely to be poor or near poor and are more likely to report fair or poor health.

Characteristics of Caregivers

Gender

National estimates substantiate the findings of numerous researchers that caregiving is primarily a female responsibility (Chart 2-1, p. 34). Approximately 72 percent of caregivers to the functionally impaired aged are female. Daughters constitute 29 percent of this population and wives comprise another 23 percent. Sons make up only 9 percent of caregivers and husbands account for 13 percent of this population. The remainder is composed of daughters- and sons-in-law, grandchildren, siblings, other relatives, friends and other unpaid helpers.

Age

The average age of the caregiver population is 57 years (Chart 2-2, p. 35). However, one-quarter is aged 65 to 74 and another 10 percent is aged 75 or older. Husbands are by far the oldest caregivers with 42 percent of them aged 75 or older. These estimates suggest that the informal care system is composed, in large part, of the "young-old" caring for the "old-old."

Marital Status

Seventy percent of all caregivers are married. Approximately one-half of the nonspousal female caregivers and the same proportion of nonspousal male caregivers are married. However, female caregivers are twice as likely to be widowed as are their male counterparts. In contrast, male caregivers are almost twice as likely as females never to have been married.

Informal caregivers of the very frail elderly population differ from the general population in the United States with respect to marital status (Charts 2-3a, 2-3b, pp. 36-37). More specifically, caregivers aged 45 to 54

years old are less likely to be married than their age peers in the overall population. Furthermore, male caregivers in this age group are four times more likely never to have been married than those in the general population. In contrast, among the older caregivers, and particularly those aged 65 and older, both males and females are more likely to be married than their age peers in the overall population, because they are caring for their spouses.

Employment

Employment status is particularly important, not only as a source of income, but because it represents a major competing demand for the attention of the caregiver. One-third of the informal caregivers assisting mildly to severely impaired elderly persons are employed (Chart 2-4, p. 38). Two out of five of the daughters and a little over one-half of the sons are in the labor force; one-third of the other female caregivers (e.g., sisters, other non-spousal relatives and friends) and 46 percent of their male counterparts also are working.

Compared to the total U.S. population in 1982, caregivers were less likely to be employed (Chart 2-5, p. 39). While 62 percent of females aged 45 to 54 were employed in 1982, only one-half of female caregivers in this age group were in the labor force. Similarly, while 42 percent of women aged 55 to 64 were working, only one-third of their caregiving age peers were employed. The disparity is even greater among male caregivers. While 90 percent of males aged 45 to 54 were employed in 1982, only two-thirds of their caregiving counterparts participated in the labor force. Among those aged 55 to 64 years, comparable figures are 70 percent and 46 percent, respectively. Finally, among those 65 years and older, 18 percent of males in the general population were employed compared with only 8 percent of male caregivers.

Economic Status

The majority of caregivers providing care to the very impaired elderly reported adjusted family incomes in 1982 which fell in the middle income bracket. However, a little less than one-third of this population had 1982 incomes in the poor or near poor category. Caregiving wives and other females (e.g., sisters, other relatives and

friends) comprised the largest portion of this economically disadvantaged subgroup of caregivers. Compared to their age peers in the general population, male and female caregivers were more likely to report adjusted family incomes below the poverty line.

Health Status

One-quarter of informal caregivers report that they are in excellent health. However, it is interesting to note that one-third of this population perceives its health status as fair or poor. Among spousal caregivers, the proportion is even higher with 44 percent of the wives and over one-half of the husbands reporting fair to poor health.

A comparison of the self-assessed health status of caregivers with their age peers in the U.S. population reveals that members of the former group perceived themselves to be in poorer health (Chart 2-6, p. 40). For example, one-third of female caregivers aged 45 to 64 reported their overall health in 1982 as fair or poor compared with slightly more than one-fifth of all females in the same age group. The disparity between male caregivers and their age peers in the general public was slightly greater. Elderly female caregivers (i.e., aged 65 years or older) were only slightly more likely than all aged females to perceive their health status as fair or poor; elderly male caregivers, however, were much more likely to rate their health status as fair than were their age peers in the U.S. population. While one cannot draw any causal inferences from these findings, one could speculate that the cumulative stresses of caregiving might contribute to a deterioration in the health status of the caregiver.

Living Arrangements

The living arrangement between the caregiver and the care recipient is a major predictor of caregiver involvement, behavior and burden. The majority of elderly persons are in relatively good health and live independently. National data indicate that approximately one-third of persons aged 65 or older live alone, 46 percent live with a spouse only and approximately one in five live with children or other relatives (Kovar, 1986). The aged consistently express a strong preference for separate living, and there is a tendency on the part of elderly

persons and their children to live near, but in separate quarters, in what Rosenmayr (1977) calls "intimacy at a distance."

However, Horowitz (1985) has pointed out that cross-sectional data are inadequate for documenting the prevalence of shared households over the lifetime of an elderly person. Therefore, the proportion of older people ever residing within an intergenerational household has been underestimated and underdocumented (Beck and Beck, 1982; Noelker and Poulshock, 1982).

National estimates of persons caring for very impaired elderly individuals indicate that a shared living arrangement is the prevalent pattern when the elderly person becomes functionally dependent (Chart 2-7, p. 41). Close to three-quarters of all caregivers live with the disabled family member or friend. Sixty-one percent of both caregiving daughters and sons report sharing households with their parent. The aged person's deteriorating health status appears to be a key factor in the decisionmaking process. For example, 38 percent of the daughters and one-third of the sons note that they would not live with their parents if the care were not needed. Furthermore, 8 percent of the caregiving children and other informal caregivers living separately from the care recipient indicate that they have moved to be closer to the disabled relative. Finally, 12 percent of the nonspousal caregivers report that they chose not to move because of the care needs of their functionally impaired aged relative.

Caregiver Involvement

Level of Responsibility

It is important to recognize that informal caregivers represent a special group of people — they have chosen, out of desire and/or necessity, to assume the responsibility for providing physical, emotional and often financial support to an elderly relative or friend whose level of dependency is likely to increase over the months or years. Approximately 70 percent of the population are primary caregivers with the remainder assuming a secondary role (Chart 2-8, p. 42). One-third of the caregivers are sole providers, 28 percent are primary

caregivers with one or more unpaid helpers and only 10 percent receive paid and unpaid assistance.

Time Commitment

The duration of caregiving ranges from less than one year to 43 years. The majority of caregivers have been providing unpaid assistance for one to four years; however, one-fifth have been caring for the disabled person for five years or more.

Eighty percent of caregivers provide unpaid assistance seven days a week. Virtually all spousal caregivers provide assistance daily; approximately three-quarters of the daughters and 71 percent of the sons devote part of each day to caregiving activities. On an average day, caregivers spend approximately four hours specifically on caregiver tasks. There is no significant difference between the amount of time spent in caregiving activities by gender.

Tasks

Caregiving activities vary widely across families and range from running occasional errands to 24-hour care. The types and amounts of care provided are dictated primarily by the disability level of the elderly care recipient, but there are other factors that also influence the care. Regardless of the level of impairment, however, virtually all caregivers provide some degree of affective assistance or emotional support through visiting and telephoning, keeping the elderly person company and "cheering up" the aged relative or friend when she or he feels depressed. In fact, adult children now provide more emotional support to their elderly parents than they did in the past (Bengtson and Treas, 1980; Hareven, 1982).

Most caregivers are involved in providing direct services to the elderly care recipient. At one end of the continuum, caregivers help with instrumental activities of daily living such as transportation and shopping. As the dependency of the older person progresses, caregivers become involved in such activities as housekeeping, meal preparation and financial management. More severely impaired persons may require personal care assistance

(i.e., bathing, feeding, dressing, and toileting) and help with such health care needs as changing bandages and taking injections.

National data confirm the wide array of tasks performed by informal caregivers (Chart 2-8, p. 43). Over 85 percent of caregivers assist elderly persons with shopping and/or transportation. Four out of five perform one or more housekeeping chores, one-half handle the finances and 53 percent administer medication and/or change bandages. Two-thirds of these caregivers also attend to the personal care needs of the care recipient including eating, bathing, dressing and/or toileting. In addition, a little less than one-half of these caregivers assist their elderly relative or friend in getting in and out of bed or moving around inside the house.

From this discussion it is clear that families and friends provide a wide range of services. Furthermore, they do not specialize or concentrate help in selected areas but tend to increase services according to the needs of their impaired aged relative or friend (Cantor, 1980).

There are, however, important gender differences in the provision of services. Women offer significantly higher levels of overall assistance (Horowitz, 1985; Stoller, 1983; McKinlay and Tennstedt, 1986). They are much more likely than males to attend to the personal hygiene needs of the care recipient including bathing, dressing and toileting, and to engage in household tasks and meal preparation. In contrast, male caregivers typically provide transportation and help the older person with home repairs and financial management.

In addition to the tasks already outlined, caregivers often assist the elderly in finding the appropriate services they need. Many caregivers are beginning to assume a linkage or mediating role which has developed in response to the growing complexity of organizational systems. This may be a particularly difficult function, however, because many families are just as uninformed as the elderly care recipient about health and social services available in the community (Brody, 1978; Shanas and Sussman, 1981). One small study of female caregivers (Archold, 1983) noted that care providers tended to be spouses while mediators, or case managers, were more likely to be adult daughters. However, several other community studies (Horowitz and Dobrof, 1982; McKinlay and Tennstedt; 1986) have found that both female and male caregivers, regardless of kin

relationship, are engaged in the linkage role to some degree.

The Impact of Caregiving

Most caregivers devote quite a bit of time and energy to providing long-term care to frail elderly relatives or friends. It is widely assumed that these responsibilities place overwhelming burdens on families, friends and neighbors, burdens which eventually wear down or erode the informal caregiving network. While it is true that the obligations inherent in caring for a disabled older person place strains on the caregiver and her/his family, it is important to remember that there is extensive variation in the caregiver's perception of this experience. Many researchers have noted that the level of burden or stress is much less than would be expected given the severity of the care recipient's disability and the multiplicity of demands placed on the caregiver.

Families and other informal caregivers seem to have a vast reservoir of coping mechanisms which mitigate against the potentially negative consequences of these responsibilities (Horowitz, 1985; Doty, 1986). Furthermore, the caregiving experience has many positive aspects which counteract the deleterious impact of providing unpaid long-term care to an increasingly dependent aged relative or friend.

The Benefits of Caregiving

Researchers have tended to focus on the negative impact of caregiving. Consequently, little attention has been paid to the benefits of the caregiving experience. This is an area that warrants additional research. However, as was noted earlier, we do know that the relationship between children and their elders is one of reciprocity and the mutual transfer of care. Brody (1985) notes that "In the main, having an elderly parent is gratifying and helpful. Older people are a resource for their children, providing many forms of assistance. Most people help their parents willingly when need be and derive satisfaction from doing so" (p. 21). For many adult children, caregiving can substitute for a failed marriage, widowhood and/or an unfulfilling work career. For elderly

spouses, the intense investment in the caregiver role may help to compensate for the loss of other roles as one ages (Doty, 1986). Therefore, caregiving often provides the caregiver with a renewed sense of usefulness.

National estimates show that almost three-quarters of the respondents report caregiving makes them feel useful (Chart 2-10, p. 44). Spousal caregivers, in particular, view caregiving as a major contribution to their self-worth. Approximately two out of three caregivers also note that the disabled relative or friend keeps them company. While this positive consequence is most prevalent among spouses, over one-half of the children also cite this benefit. A little more than one-quarter of the caregivers report that the care recipient helps with household chores and one in four indicates that the elderly relative or friend provides financial assistance in the form of gifts and/or cash. Only a small proportion (5 percent) notes that the care recipient provides babysitting assistance.

In addition to these benefits, caregiving also may result in an improved relationship between caregiver and care recipient and a better understanding of the impaired relative or friend. Furthermore, the caregiver experience helps to put other stresses into perspective, and thus may enhance one's sense of well-being and one's world view.

The Negative Aspects of Caregiving

Case studies and survey research substantiate the fact that many caregivers are burdened by the responsibilities and demands associated with providing long-term care to a disabled relative or friend. Many studies have documented that the degree of caregiver stress increases as the older person's level of functional impairment becomes more severe (Cicirelli, 1981; Horowitz, 1985; Noelker and Poulshock, 1982). Disruptive behaviors associated with dementia are particularly distressing for families (Crossman et al., 1978). Not surprisingly, the stresses of caregiving also are more severe among those sharing a household with the disabled person, an association which is attributed, in large part, to the higher levels of impairment and the greater time commitment required to meet the care needs of the aged individual.

1. Sources of Stress

a. Personal Limitations: The limitations on one's personal life represent one major source of stress for caregivers (Chart 3-11, p. 45). Restriction of one's social life is the most frequently cited problem among caregivers assisting moderately to severely impaired persons. Close to one-half of all caregivers report this limitation; caregiving wives and daughters are more likely than husbands and sons to note that caregiving has impeded their ability to engage in an active social life.

Recent research at Duke University corroborates these national estimates. George and Gwyther (1986) compared the social activity levels of a sample of individuals caring for Alzheimer's disease victims with the activity levels of several community-based samples. They found that caregivers were less able to pursue an active social life than were their peers in the general public.

Infringement of privacy appears to be a problem for close to one-quarter of caregivers assisting the frail aged; daughters, in particular, find that caregiving responsibilities restrict their privacy. Approximately one in three caregivers also report that the constant attention required by the older person limits the time one has for personal activities.

b. Competing Demands — Familial Obligations and Work Conflict: Most caregivers assume a number of roles in addition to their responsibilities as a caretaker of a frail elderly relative or friend. Much of the literature on informal caregiving has been concerned with the potentially competing demands placed on caregivers who attempt to juggle multiple roles. The potential for role conflict is particularly great among middle-aged daughters and daughters-in-law, who frequently are parents, housekeepers and workers as well as primary caregivers to frail elderly parents. This group of caregivers has been labeled the "women in the middle" or the "sandwich generation" (Brody, 1985) because their precarious position between generations, both literally and figuratively, increases the likelihood that they will experience competing demands.

According to national estimates, there are approximately 166,000 women who provide elder care and child care simultaneously. Moreover, 40 percent of these

"women in the middle" are employed. As more women choose to delay their childbearing and enter the labor force, the size of the "sandwich generation" is likely to increase.

Research suggests that competing familial obligations do not reduce the amount of time daughters devote to caring for an elderly parent. Rather, caregivers tend to double up on their responsibilities and to cut back on their leisure time in order to fulfill all of their caregiving tasks. One small study of employed female caregivers in Massachusetts (Gibeau, 1986) estimated that while the typical respondent spent an average of 12 hours per week caring for an elderly family member, she spent over twice that time, or 26 hours per week, caring for her home. This left her with a weekly combined average of 38 hours or the equivalent of a full work week.

Employment also represents a potentially conflicting demand for caregivers. In a recent survey of its home office employees, The Travelers Companies (1985) found that an estimated 20 percent of its workers aged 30 or older provide some form of care to an older person. Almost ten percent of these caregivers report spending 35 hours or more a week at this task, in addition to the 37-hour work week at Travelers.

The general consensus among caregivers and care recipients is that caregiving should not interfere with labor force participation. Female participants in a small study of three generations in Philadelphia (Brody et al., 1983) agreed that it is better for a working woman to pay someone to care for her parent than for her to leave her job to assume caregiving responsibilities. Women of the middle generation were more likely than those in the younger or older generations to expect working daughters rather than sons to adjust their work schedules for parent care.

National estimates indicate that a relatively small proportion of caregivers actually quit their jobs to assume the caregiver role. Approximately 11 percent report that they left the labor force specifically to become a caregiver. One out of four have been out of work for one year or less, almost 40 percent have been unemployed for two to four years and a little more than one-third have been out of the labor force for five years or more.

These figures, however, do not capture the full magnitude of the conflict between work and caregiving.

Many companies do not have policies sensitive to the problems of working caregivers. As a result, employees may experience a high level of stress associated with their competing demands. For example, a recent article in the Washington Post (1986) documented the experience of an employee at the Allied-Bendix Aerospace Factory in McLean, Virginia. He received an emergency call from a nearby hospital with the news that his mother's health had reached a crisis state. However, when the employee requested permission to leave, he was told he would be fired if he left his job. He had already accumulated a number of "absentee points" and one more would mean termination.

This example reflects the worst case scenario resulting from conflict between employment and caregiving. A sizeable proportion of working caregivers do, in fact, alter their work situation in some way to accommodate their caregiving responsibilities. National estimates of caregivers to the frail elderly indicate that among those who have worked during the caregiving experience, one-fifth have cut back on hours, 29 percent have had to rearrange their schedules and a little less than one in five have taken time off without pay (Chart 2-12, p. 46). Wives are more likely than husbands to rearrange their schedules. Daughters are more likely than sons to use all three types of solutions to resolve their work conflict. Among those who have taken unpaid leave, approximately 10 percent were out of work less than one day during their last episode, seven out of ten were on leave for one to five days and one-fifth of these caregivers were on unpaid leave for more than five days.

The type of work conflict varies by occupation. For example, among female primary caregivers (Chart 2-13, p. 47), clerical and sales workers are more likely than other types of employees to reduce their number of working hours. Similarly, clerical and sales workers and, to a lesser extent, caregivers in professional or managerial positions, are more likely to rearrange their schedules than are service workers or those in blue collar (i.e., operative, laborer) occupations. In contrast, blue collar employees are much more likely than any other category of worker to take time off without pay. While the relationship between occupation and work conflict warrants more empirical investigation, these observations suggest that employment policies operating in a particular occupational setting may

influence the choices individuals have in meeting their caregiving responsibilities.

While it is clear that a sizeable proportion of working caregivers experience role conflict, the degree to which employment impinges on caregiving responsibilities is debatable. For example, studies using aggregate data on a community level (Nardone, 1980; Soldo and Sharma, 1980) have identified women's labor force participation as a significant factor influencing rates of institutionalization of elderly persons. Findings from several community studies, however, indicate that employment status is not related to the overall amount of help provided (Brody, 1981; Cantor, 1980; Noelker and Poulshock, 1982). Among a random sample of caregivers living with disabled elders in northeastern New York, Stoller (1983) found gender differences in the impact of employment on level of parental caregiving. Specifically, she observed that being employed decreased the average level of a son's assistance by over 20 hours per month while employment was not a significant predictor of caregiving hours among daughters.

c. The Care Recipient's Emotional and Physical Demands: The emotional and physical demands of the care recipient also represent potentially significant sources of stress for informal caregivers. Family members, friends and neighbors cite several dimensions of disruptive behavior as problematic. More than three-fifths of the caregivers are bothered by the confusion and forgetfulness exhibited by their aged care recipient. A little less than one-half of the caregivers, principally wives and daughters, report that their sleep is interrupted by the erratic behavior of the care recipient. Approximately one in three notes that the elderly relative or friend frequently becomes agitated and yells at the caregiver, and one-quarter of the caregivers report that the care recipient acts "senile." Furthermore, one-fifth of these informal care providers, particularly the wives and daughters, find that the care recipient's behavior is embarrassing.

Many caregivers also report problems with the physical demands placed on them by the care recipient. For example, a little over one-third of the caregivers have difficulty lifting or moving their elderly relatives or friend

In addition, close to two-fifths of these caregivers, and in particular the females, report that helping the care recipient when they are feeling ill is a problem.

2. Caregiver Strain

The combination of personal limitations, competing role demands and the stresses generated by the care recipient's behavior and physical demands creates various levels of emotional, physical, financial and familial strain for informal caregivers.

a. Emotional Strain: Findings from numerous studies indicate that the most pervasive negative consequence of caregiving is the emotional strain generated by the burdens placed on the caregiver. Caregivers frequently report symptoms of depression, anxiety, feelings of helplessness and lowered morale and emotional exhaustion (Cantor, 1983; Danis, 1978; Frankfather et al., 1981; Stephens and Christianson, 1986). In their study of caregivers assisting Alzheimer's disease victims, George and Gwyther (1986) found that caregivers reported three times as many emotional stress symptoms as the general population. Furthermore, caregivers were two to three times more likely than their peers in the general population to take psychotrophic drugs. Twelve percent also admitted that they used alcohol as a way of coping with the strains of caregiving.

Data from the 1982 Long-Term Care Survey reveal that females are much more likely than males to report emotional strain associated with caregiving (Chart 2-14, p. 48). Over half of the wives report that caregiving is an emotional burden as compared with only 40 percent of the husbands. Similarly, almost one-half of the daughters report emotional strain compared with less than one-third of the sons.

b. Physical Strain: The caregiver has frequently been referred to as "the hidden patient" (Fengler and Goodrich, 1979), a label which suggests that caregiving may have negative consequences for the physical health status of the caregiver. The evidence, however, is weak and equivocal. National estimates of caregivers assisting the frail aged population, for example, indicate that only 16 percent cite caregiving as a contributor to a decline in

their health status. Caregiving wives are more likely than other relatives or friends to report physical strain with over one-quarter of them reporting that their health has worsened as a result of caregiving responsibilities.

As was noted previously, a comparison of the self-assessed health status of these caregivers with their age peers in the general population reveals that their general health is, in fact, poorer than the norm. However, we cannot make any causal inferences from this comparison. Furthermore, this comparison contradicts the findings from a study of caregivers assisting relatives stricken with Alzheimers disease (George and Gwyther, 1986) which found that the level of physical health among the caregivers was as high as that reported among several random community samples.

Results from another small longitudinal study of caregivers with matched controls (Danis, 1978) indicate that the caregivers had fewer health problems than the control group. In an effort to explain this finding, the author of that study suggests that the overwhelming responsibilities of caring for a disabled older person may help the caregiver to shift attention from his or her own health problems to the needs of the care recipient.

c. Financial Strain: Findings from numerous studies indicate that the financial strain reported by families and other unpaid helpers is much lower than expected. The 1982 Long-Term Care Survey provides information on the amount of money nonspousal caregivers spend on the care of a disabled elder (Chart 2-15, p. 49). More than one-half of the nonspousal caregivers report spending nothing extra per month. One-fifth spend less than $50 monthly, 15 percent spend $50 to $100 and only 8 percent spend more than $100 per month on caregiving activities. Further, less than one-fifth of all caregivers report that the care costs more than they can afford. The perceived financial burden is greatest among spouses with one in four reporting high levels of economic strain.

The relatively low proportion of caregivers citing financial hardship should be interpreted with caution. We know that families frequently underreport the degree of economic strain experienced because they feel that they should absorb the costs of care for a dependent elder who, in the past, has provided so much financial and emotional support. In addition, for the great majority of caregivers

who are living with the care recipient, it is difficult, if not impossible, to separate the costs of caregiving (including food and shelter) from overall family expenses. Moreover, research on informal caregiving has only examined the degree of financial burden at one point in time. It is likely that economic strain increases over the months and years of providing long-term care to a chronically disabled older person.

There are other hidden costs of caregiving which place financial burdens on the individual and society. As was noted previously, a sizeable proportion of caregivers, and middle-aged daughters in particular, have either quit work or experienced some degree of work conflict. Women who experience interrupted careers not only lose wages but are likely to earn less retirement income because the erratic pattern of their work decreases their opportunity to achieve pension vesting rights. Divorced or widowed female caregivers who have to leave the labor force to care for a disabled parent or other relative also are likely to lose their health insurance coverage. The consequent loss of wages and benefits are seen as contributing factors to the "feminization of poverty" among older women (Minkler and Stone, 1985).

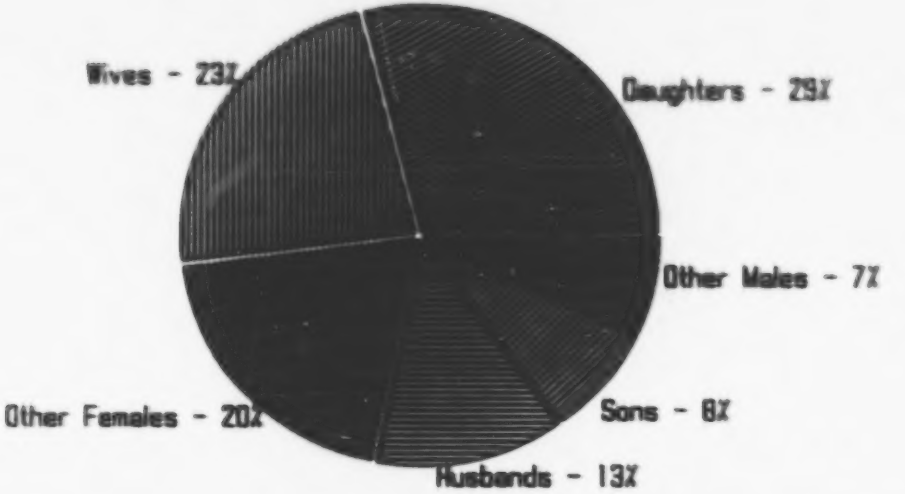
On a societal level, the loss in productivity associated with caregiver/work conflict places a financial burden on employers. The public coffers also are strained by the loss of tax contributions and the increased costs of public assistance to formerly employed caregivers.

d. Family Strain: Besides the emotional, physical and financial strain on the individual, the caregiving experience may have a significant impact on family relations. National data from the Long-Term Care Survey indicate that approximately one-quarter of the caregiving children and almost one-third of other nonspousal caregivers have dependent children (i.e., less than 18 years old) living at home. Many have hypothesized that the competing demands of child care and elder care may generate caregiver overload. Spending time away from one's family is a major concern for a large proportion of informal caregivers (Archold, 1983; Stephens and Christianson, 1986). There also is evidence that elder care creates family conflict and disruption although the magnitude of this conflict is the subject of some debate (Horowitz, 1985). Several studies have found that the

reduced time spent with families did not result in major family disruptions (Horowitz and Dobrof, 1982; Cantor, 1980). Others (Archold, 1980; Frankfather et al., 1981) have suggested that family conflict may arise among siblings sharing the care responsibilities for an elderly parent. Strain among siblings also may be created when one is a primary caregiver and the other is uninvolved.

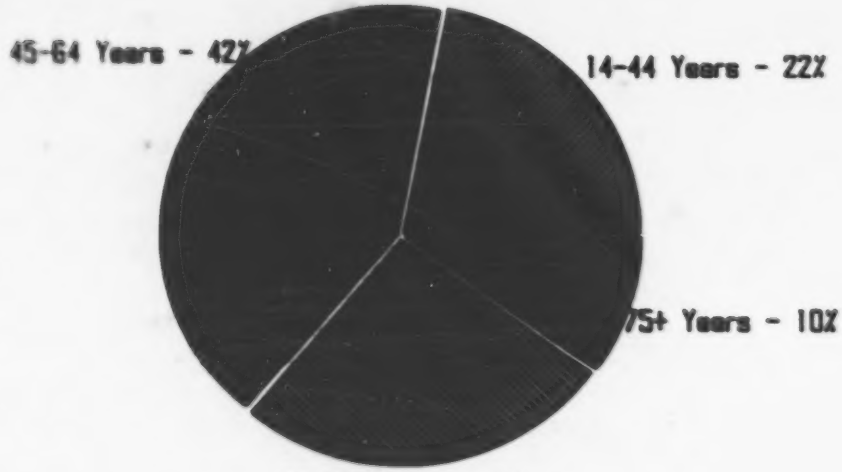
A few researchers have observed increased strain between the caregiver and the care recipient (Archold, 1983; Noelker and Poulshock, 1982). There also is some evidence that caregivers, and daughters in particular, comprise a substantial proportion of elder abusers (Mutschler, 1985). The interdependence of caregiver and care recipient appears to be the pivotal factor in the abuse syndrome. More specifically, the level of dependency of the abused older person is less important in the abusive pattern than the dependency of the abusive caregiver on the care recipient. Financial dependency of the caregiver, in particular, has been identified as a major correlate of elder abuse.

Distribution of Caregivers by Relationship to Elderly Care Recipient



Note: Caregiver population includes primary and secondary caregivers.

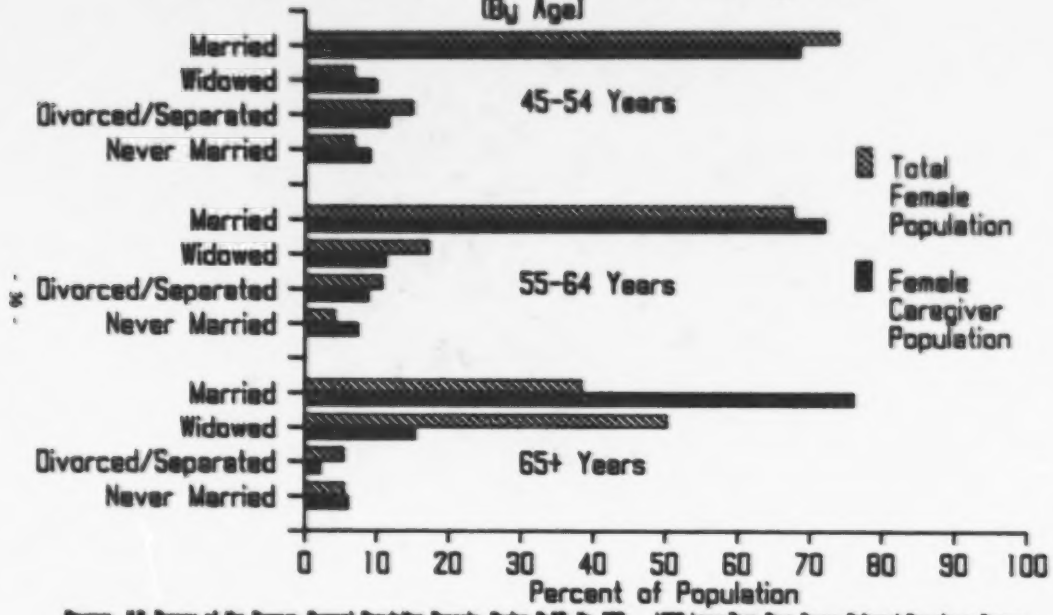
Distribution of Caregivers By Age



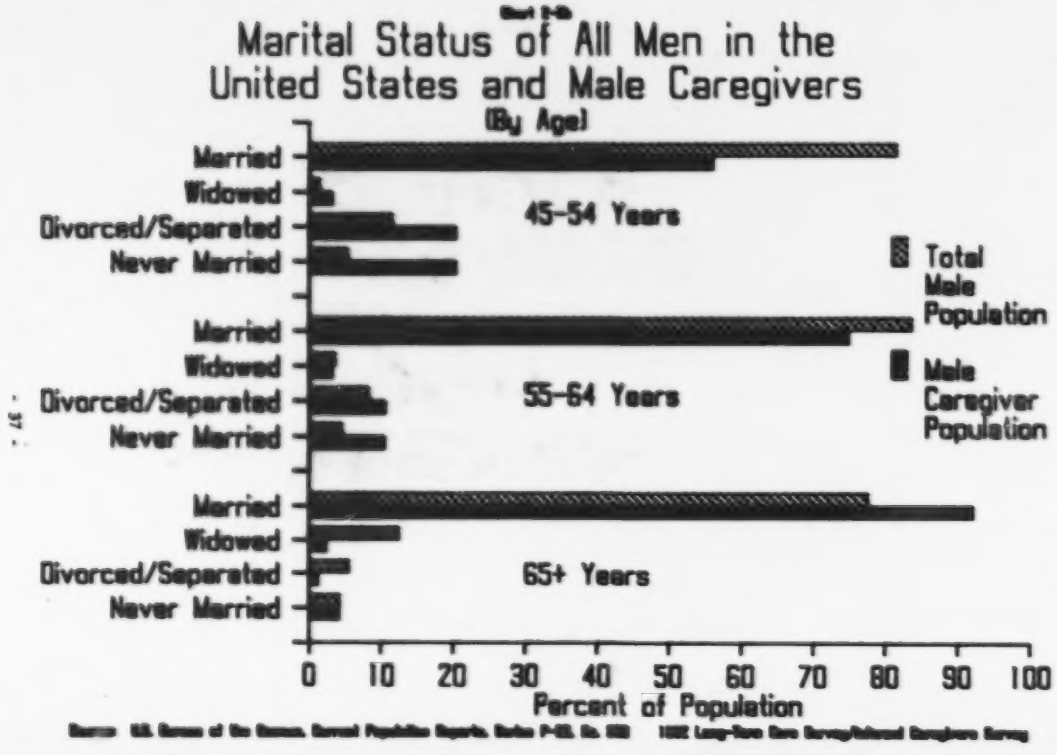
Note: Mean Age is 57.3 Years

Marital Status of All Women in the United States and Female Caregivers

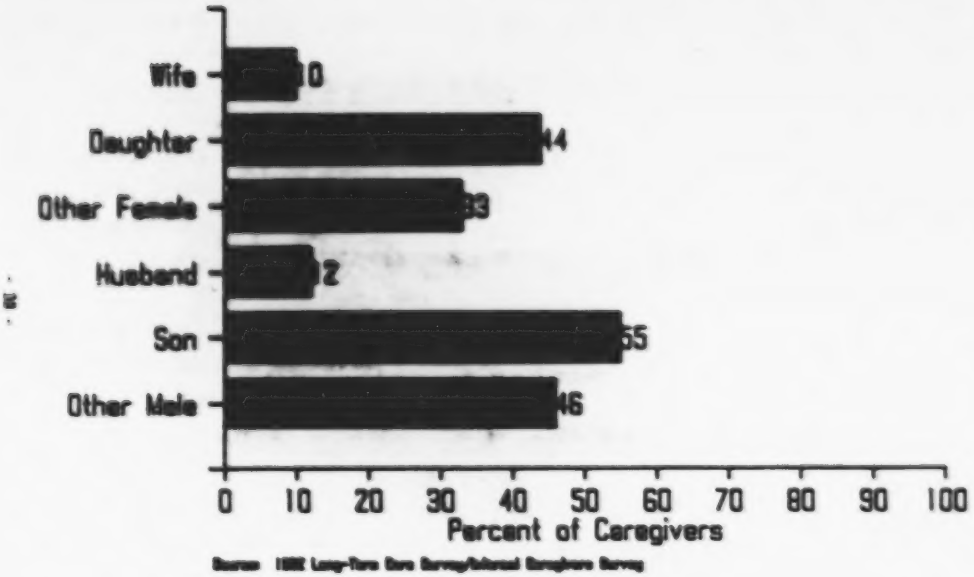
(By Age)



Source: U.S. Bureau of the Census, Current Population Reports, Series P-23, No. 159; 1982 Long-Term Care Survey/National Caregivers Survey


Marital Status of All Men in the United States and Male Caregivers
(By Age)
Married
Widowed
Divorced/Separated
Never Married
45-54 Years
Married
Widowed
Divorced/Separated
Never Married
55-64 Years
Married
Widowed
Divorced/Separated
Never Married
65+ Years
Total Male Population
Male Caregiver Population
0
10
20
30
40
50
60
70
80
90
100
Percent of Population

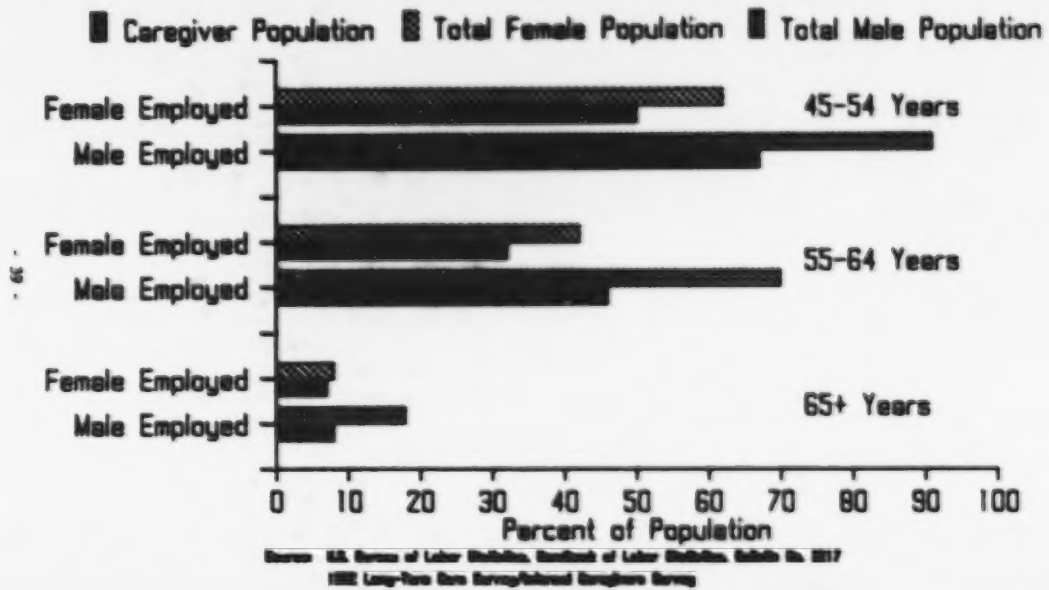
Percent of Caregivers Who are Employed



Sheet 2-3

Percent of People in the Total U.S. Population and Caregiver Population Who Are Employed

(By Age and Gender)

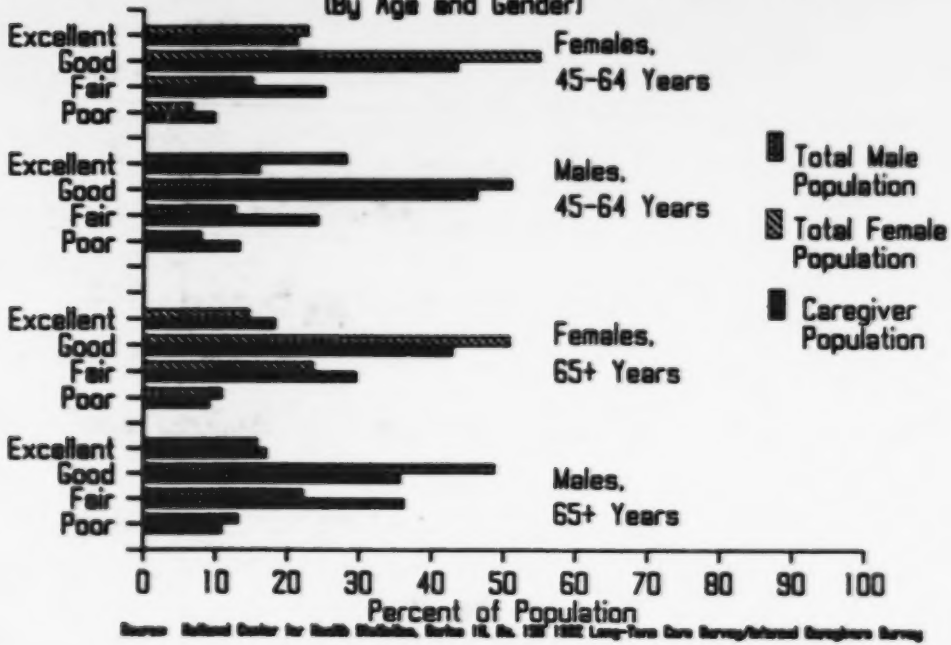


Source: U.S. Bureau of Labor Statistics, Handbook of Labor Statistics, Bulletin No. 2217
1982 Long-Term Care Survey/Informal Caregivers Survey

Chart 2-6

Self-Assessed Health Status of Total U.S. Population and Caregiver Population

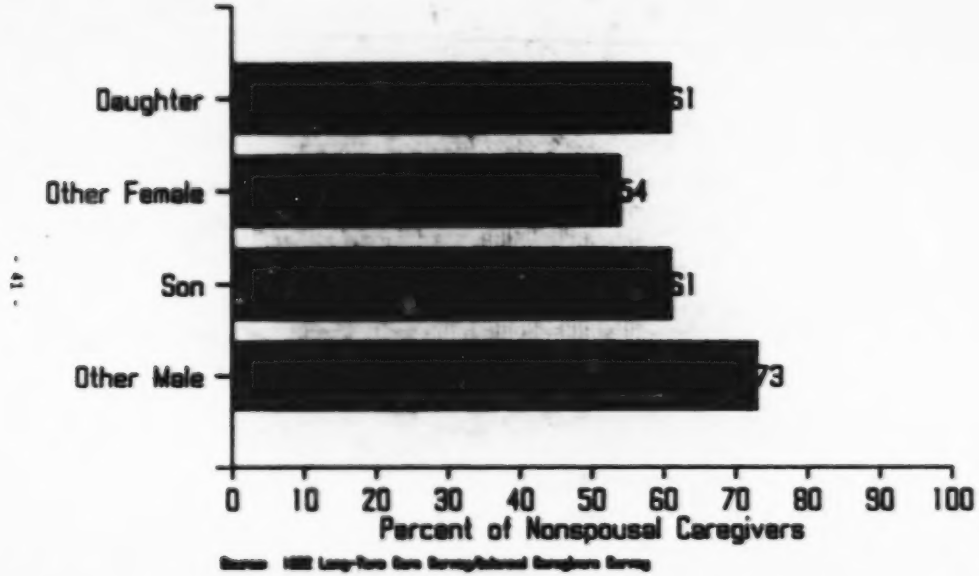
(By Age and Gender)



Source: National Center for Health Statistics, Series 10, No. 180, 1992 Long-Term Care Survey/Informal Caregivers Survey

Chart 2-7

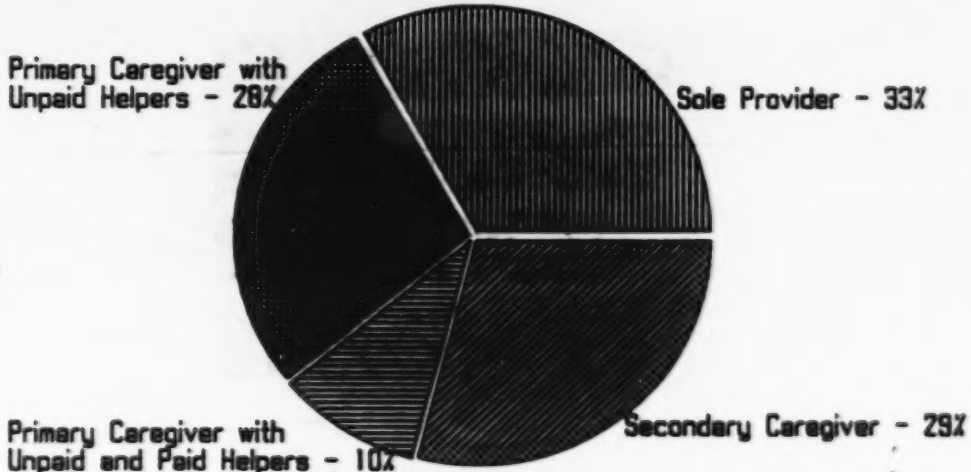
Percent of Nonspousal Caregivers Sharing Households with Care Recipients



Source: 1988 Long-Term Care Survey/Informal Caregivers Survey

Chart 3-3

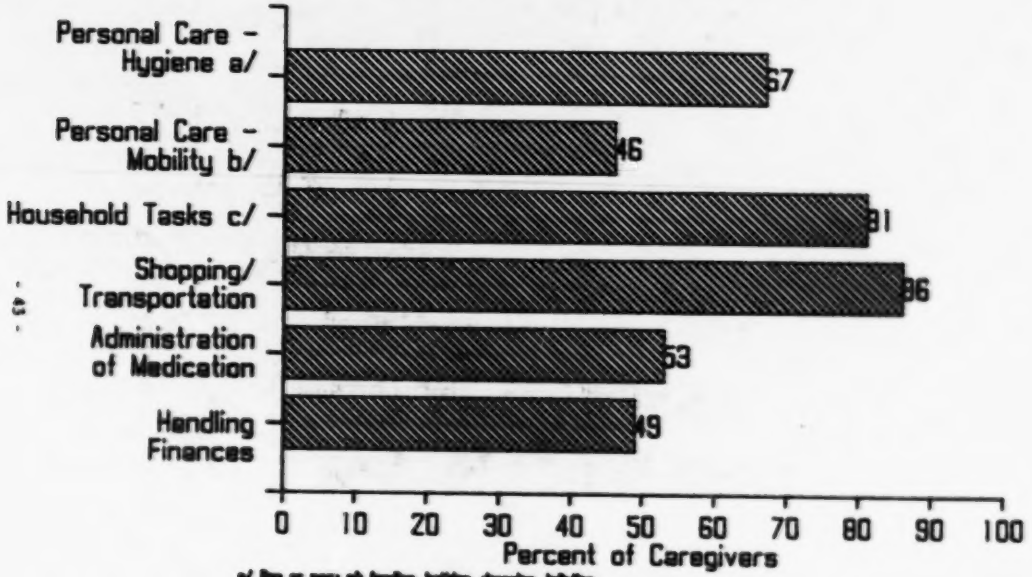
Distribution of Primary and Secondary Caregivers and Use of Outside Help


Primary Caregiver with Unpaid Helpers - 28%
Sole Provider - 33%
Primary Caregiver with Unpaid and Paid Helpers - 10%
Secondary Caregiver - 29%

Source: 1982 Long Term Care Survey/Informal Caregivers Survey

Chart 2-6

Tasks Performed by Caregivers



a/ [illegible]

b/ [illegible]

c/ [illegible]

Source: [illegible]

Benefits of Caregiving -- Contributions of Care Recipients

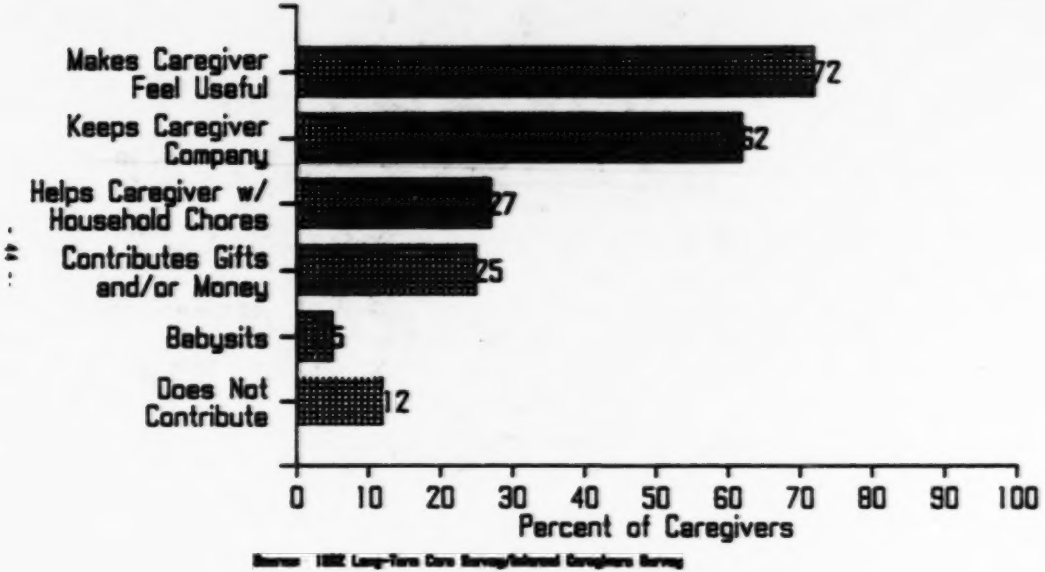
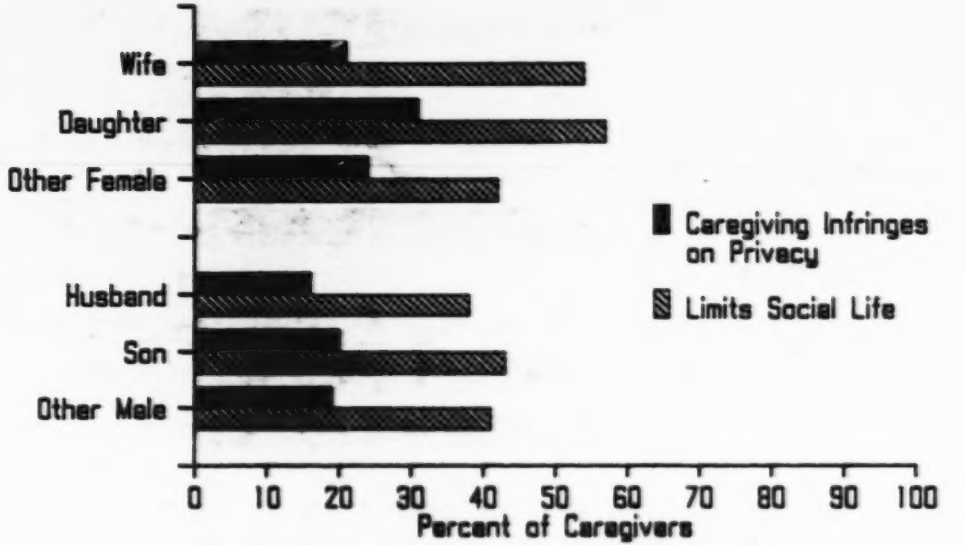


Chart 9-11

Percent of Caregivers Reporting Limitations on Personal Life



Source: 1982 Long-Term Care Survey/Informal Caregivers Survey

Methods of Resolving Work Conflict Among All Employed Caregivers

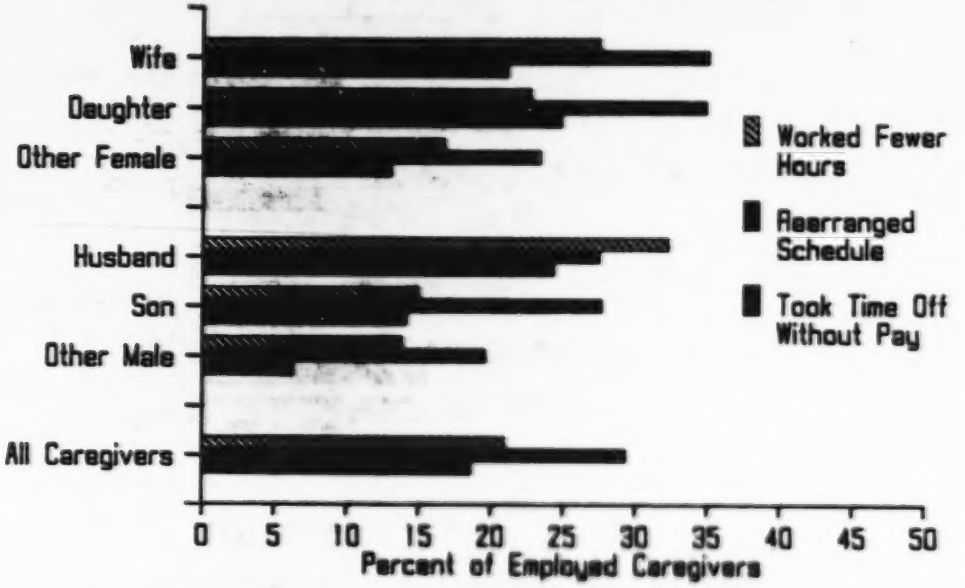
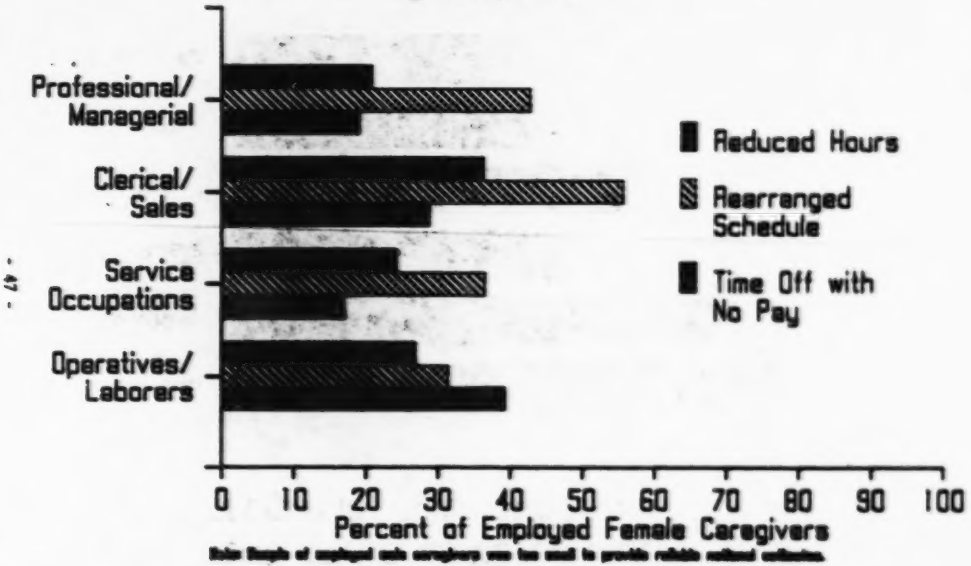


Chart 2-13

Methods of Resolving Work Conflict Among Employed Primary Female Caregivers

(By Occupation)

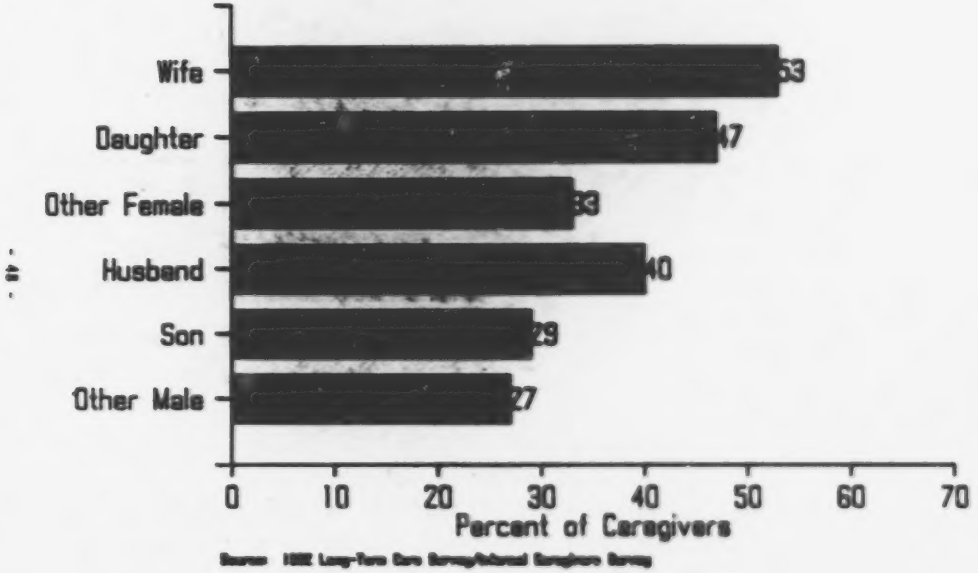


Data Sample of employed male caregivers was too small to provide reliable national estimates.

Source: 1982 Long-Term Care Survey/Informal Caregivers Survey

Chart D-14

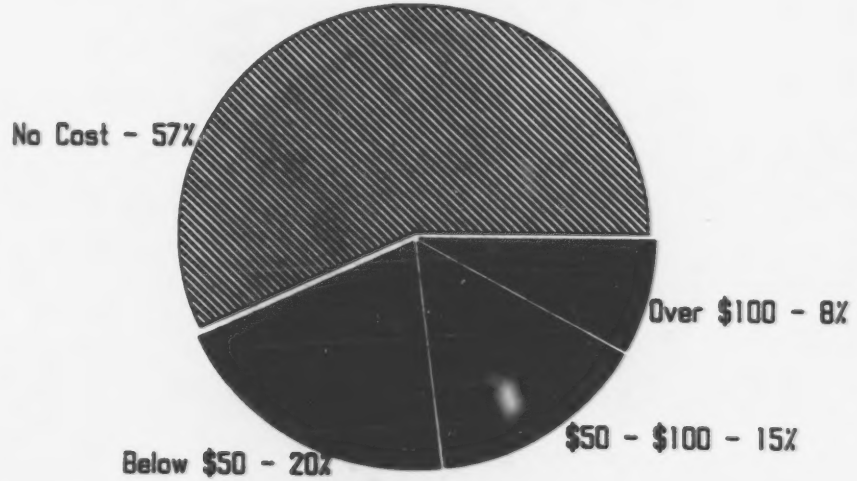
Percent of Caregivers Reporting that Caregiving is Emotionally Difficult



Source: 1982 Long-Term Care Survey/National Caregivers Survey

Chart 2-15

Average Monthly Cost of Caregiving Reported by Nonspousal Caregivers



Source: 1982 Long Term Care Survey/Informal Caregivers Survey

IV. INFORMAL CAREGIVING: THE ROLE OF THE PUBLIC AND PRIVATE SECTOR

The major issue confronting policymakers concerned about the long-term care needs of an aging population is how to design, finance and implement a system of formal care which supports and complements the array of services already being provided by informal caregivers. This is a complex problem, one which has generated much debate in recent years about the nature and direction of policies and programs to be developed.

Status of Current Public Policies

At the present time, informal caregivers provide the bulk of long-term care services to their elders with little support from public programs. For example, both the Medicare and Medicaid programs have a strong institutional bias, Medicare toward hospital reimbursement and Medicaid toward reimbursement for nursing home care. Only those Medicare beneficiaries who are confined to their homes and need skilled nursing care on a part-time or intermittent basis are eligible for home health care services provided by a Medicare-certified agency. There are no provisions for personal or custodial care, the type and level of care most frequently needed by frail and/or chronically disabled elderly persons.

Under Section 2176 of the Omnibus Budget Reconciliation Act of 1981, states are allowed to request Medicaid waivers from the Health Care Financing Administration in order to provide home and/or community-based services to impaired elders. States must demonstrate that the costs of such services do not exceed the costs of comparable care in a nursing home. As of April 1986, 46 states had received approval for waivers to cover personal care, respite care and other noninstitutional services. While these waivers have the potential to make home and community-based services available to elders and their families, few programs are statewide.

The Federal government also provides funds for noninstitutional services through Title III of the Older Americans Act (OAA). In-home care, such as homemaker, home health aide and chore services, is a priority service.

Under the OAA, home-delivered meals also have grown in importance. The ability of the OAA to complement the efforts provided by informal caregivers is limited, however, due to its relatively small level of resources as compared to other programs. The Social Services Block Grant also provides limited funds for community-based services designed to prevent or reduce inappropriate institutionalization.

Certain provisions in current public policies may have the unintended consequence of creating disincentives for families to provide care to their disabled relatives. A prime example of such impediments is the requirement of the Federal Supplemental Security Income program (SSI) that elders living in the household of another individual or family must receive a one-third reduction in monthly benefits. This provision serves as a disincentive to families who want to care for a disabled person in their homes.

Another example is the Medicare home health care regulation which restricts coverage to intermittent care, thereby discouraging families from paying for supplemental services. That is, if the family chooses to pay for additional hours of nursing care not covered by Medicare, then the care may not be deemed intermittent and Medicare can deny all home health care benefits.

Two provisions in H.R. 3838, the Tax Reform Act of 1986, also represent potential disincentives for family care. Under the old law, an impaired elderly person could claim a personal exemption while at the same time being claimed as a dependent on another taxpayer's (e.g., daughter or son) return. According to the new law, the personal exemption is no longer allowed when an elderly individual is claimed on another taxpayer's return. In addition, the increase in the floor under the medical expense deduction from 5 percent to 7.5 percent of the taxpayer's adjusted gross income will make it more difficult for families to claim the Child and Dependent Care Credit. The change in the medical expense deduction provision will require the caregiver to spend more resources for the medical care of an elderly dependent in order to be eligible for the credit.

Public Sector Support for Informal Caregivers

As policymakers begin to recognize the pivotal role of the family, friends and neighbors in helping to maintain disabled elderly persons at home, they are exploring a number of service options and financial strategies to bolster the informal care system.

Service Strategies

Public policies can promote informal caregiving by supporting the development of services targeted to family members and other unpaid helpers who assist impaired elderly persons. These services run the gamut from support groups, counseling and training programs to subsidized respite care.

The little information which is available on service utilization indicates that families tend to purchase services only when the responsibility of elder care becomes too difficult for them to handle alone or with additional unpaid help. Further, when they do approach formal service providers, they are modest in their service demands, often requesting far less assistance than professionals would have recommended. Thus, the fear expressed by many policymakers that families will "come out of the woodwork" if services are made available is largely unfounded.

There is concern among policymakers that policies aimed at providing formal services to caregivers and care recipients may encourage caregivers to substitute paid care for informal care. Few studies have examined this "substitution effect"; however, the existing research has found little evidence to substantiate this concern (Gonyea et al., 1982; Sklar and Weiss, 1983).

Some have suggested that the provision of formal services in selected areas may allow caregivers to focus their attention on other care needs which they are better equipped to handle (Greene, 1983; Litwak, 1985). In a study of a random sample of disabled older persons and their caregivers in eastern Massachusetts, McKinlay and Tennstedt (1986) found that families using formal services provided the same amount of help but in different areas. Other researchers examining the impact of the use of homemaker services on the provision of informal care in New York (Frankfather et al., 1981) found that families

tend to shift their responsibilities to other activities which complement homemaker chores.

The degree to which substitution is judged as desirable or undesirable depends upon the goal of the formal service program which is being implemented. If the major objective is to provide supportive services to informal caregivers, then substitution would be considered undesirable. If, on the other hand, formal services are designed to provide respite to the informal caregiver to alleviate burden, then substitution may be a desired outcome. In the long run, the substitution of formal for informal care may be seen as beneficial if it results in the delay or prevention of costly institutionalization of the elderly care recipient.

1. Support Groups

Support groups have proliferated in response to the growing recognition that families need to acquire and/or sharpen their coping skills in order to deal with the long-term demands of a chronically disabled elderly relative. These peer programs (e.g., the Alzheimer's Disease and Related Disorders Association) have emerged primarily at the grass roots level as caregivers themselves have come to realize that their best coping mechanism is the sharing of experiences. Recent Federal and state legislative initiatives have encouraged the further development of these programs.

2. Counseling, Education and Training

Counseling, education and training programs also have received public sector support. They are designed to help families cope with conditions (e.g., behavioral disturbances, incontinence) which have been identified as precipitating factors in the decision to institutionalize a disabled elderly individual. While there have been few systematic evaluations of these programs, the evidence suggests that counseling, training and education have been successful in helping families to cope with the problems posed by stroke (Mykyta et al., 1976) and Alzheimer's disease (Lazarus et al., 1981).

3. Respite Care Services

Numerous studies indicate that respite care is the preferred service intervention for helping to alleviate caregiver burden. Respite care refers to the short-term, substitute care provided in or outside the home on behalf or in the absence of the primary caregiver for the purpose of offering a period of relief from the constant care of a chronically disabled elderly individual. While the services are intended to assist the frail and/or disabled elderly person, the primary beneficiary is the informal caregiver.

Respite care programs vary with respect to setting, duration, level of care and staffing patterns. Care is provided in the home, in community-based centers (e.g., senior citizen centers, adult day care centers) and in institutions (e.g., personal care homes, nursing homes, hospitals). The length of service ranges from a few hours per day or week, to overnight care to several days or weeks per episode. Moreover, care can be provided by volunteers or paid staff, although much lower levels of care (i.e., companion and chore services) are generally offered by the former.

The Federal and state governments have supported several demonstrations which have examined the feasibility of different respite care models. To date, however, most of the evaluative information about respite care programs has been based on ancedotes or descriptive analyses of small, non-representative samples. Therefore, little is known about attitudes toward and the demand for respite care by caregivers, the role of respite care in reducing caregiver burden, and the importance of respite services in deterring or postponing the decision to institutionalize an impaired elderly family member.

Financial Strategies

There are a number of financial assistance programs currently available in the public sector which are designed to support family members caring for an impaired elder. The major strategies are direct payments to informal caregivers for their services rendered to an aged individual and tax allowances. The money received through cash grants or tax allowances can be used at the discretion of the family to purchase services or to cover other expenses that would ordinarily be out-of-pocket. Economic

programs may be seen as ways to offset the costs of certain foregone opportunities such as the loss of wages or free time for personal errands. Tax subsidies are particularly appealing because they do not require the establishment of specific Federal or state programs to administer the benefits.

The financial incentive approach assumes that there is a demand for economic assistance. In fact, as was noted previously, findings from numerous studies indicate that financial burden is reported by a minority of caregivers. Further, when asked to choose between financial and service options, services are overwhelmingly preferred over economic assistance.

The financial approach also assumes that there is a market of services which are accessible and available for purchase. In reality, community-based long-term care tends to reflect a fragmented patchwork of programs, with little coordination and limited accessibility in many geographic areas. Despite these limitations, however, proponents of financial strategies emphasize the flexibility these programs afford caregivers in arranging for the care of an elderly care recipient.

1. Cash Payments

A recent national survey of state agencies (Linsk et al., 1986) found that 35 states permit some form of payment to relatives for the provision of home care to elderly clients. This financial incentive usually is restricted to clients at very high risk of institutionalization. Some programs grant the aged person total discretion in hiring a caregiver. In states which supplement the Federal SSI benefit, elderly care recipients may be permitted to use this supplement to reimburse a caregiving relative. On the opposite end of the continuum, selected programs are designed to protect the interests of the client by, for example, restricting reimbursement to only those relatives who are licensed care providers.

Among the 15 states with no payment to family caregivers, the most frequently cited reason is the Federal Medicaid regulation prohibiting the payment of relatives through the definition of Personal Care Services. Several agencies also note their state's own prohibition as a reason for disallowing payments to relatives.

2. Tax Allowances

Caregiving taxpayers have access to three mechanisms in the Federal income tax system: the exemption, the deduction and the tax credit (Burwell, 1986). The primary tax allowance available to households with elderly dependents is the Child and Dependent Care Credit. Under the Economic Recovery Tax Act of 1981, expenditures for the noninstitutional care of a disabled spouse or other dependent were considered eligible for the credit.

The tax credit is restrictive, however, in that the caregiver and elderly dependent must meet the following criteria:

1) the dependent must spend at least eight hours daily in the taxpayer's home;

2) the dependent must be physically or mentally incapable of caring for him or herself;

3) all taxpayers in the household must be gainfully employed; and

4) only expenses up to a maximum of $2,400 per dependent are eligible for the credit.

The credit is progressive in that individuals with lower incomes can claim a higher percentage of their dependent care expenses than persons with higher incomes. However, the credit is not refundable; that is, the amount of the credit cannot exceed the total tax liability of the taxpayer. Consequently, many low-income households are ineligible.

In fact, according to the criteria specified above, the majority of the two million caregivers represented in the 1982 Long-Term Care Survey would not be eligible for this tax credit. That is, only one-third are employed and one-quarter do not live with the care recipient. There have been several legislative proposals in Congress which would loosen the current restrictions on the existing Dependent Care Tax Credit. The broadest proposal would not require elderly dependents to be functionally impaired in order for family members to claim the credit. Others would eliminate the employment criterion and/or the

shared household requirement or offer those eligible more financial support.

Since 1979, four states have legislated tax allowances for family caregivers (Burwell, 1986). Oregon provides for a tax credit of up to 8 percent of expenses for the care of an elderly dependent (maximum credit of $250) in households with incomes below $17,500. Idaho allows households that maintain an elderly relative and provide for over one-half of the support to take a standard deduction of $1,000 or a refundable tax credit of $100. Iowa permits taxpayers to deduct from their income up to $5,000 in expenses attributable to the care of an elderly dependent living in the same household; the care recipient, however, must be a Medicaid enrollee or Medicaid eligible. Arizona permits taxpayers to deduct eligible medical expenses for an elderly person living in the state; eligibility is not restricted to relatives. This benefit recognizes the migration of elders to Arizona, many of whom are being cared for by friends and neighbors in the absence of family.

Federal Legislation Related to Informal Caregiving

A number of Federal legislative initiatives have been proposed and/or enacted which address the concerns of informal caregivers. Some focus on creating a greater awareness of the important role of families, friends and other unpaid helpers in providing long-term care. Others support research and evaluation activities designed to examine alternative ways of dealing with the problems of informal caregiving. Several encourage the development of services targeted to the needs of family caregivers. Many recent legislative efforts have focused specifically on families caring for victims of Alzheimer's disease.

1. Older Americans Act Amendments of 1984

The Older Americans Act Amendments of 1984 target several provisions to families caring for Alzheimer's disease victims. Title III includes, within the priority service category of in-home services, reference to supportive services for families of elderly victims of Alzheimer's disease. Under the Title IV training authority, special consideration is to be given to projects for the

recruitment and training of personnel and volunteers who provide respite care to families of Alzheimer's disease victims. Similarly, the Title IV demonstration authority requires that the Commissioner of the Administration on Aging give special consideration to projects designed to meet the supportive services needs of these families.

2. National Family Caregivers Week

The 99th Congress recently passed a joint resolution, signed by President Reagan, proclaiming the week beginning November 24, 1986, as "National Family Caregivers Week." This national week of celebration affirms the vital importance of the family caregiver and recognizes the contribution made by the family in maintaining frail and disabled elderly relatives at home.

3. Domestic Volunteer Service Act Amendments of 1986

The Domestic Volunteer Service Act Amendments of 1986 focuses on the role of volunteers in relieving the burden of caregiving. This bill requires ACTION to evaluate the impact of the Senior Companion Program on care recipients and their families. Issues to be addressed by this evaluation include 1) the range and extent of service needs and services provided to family caregivers assisted by volunteers; 2) the extent to which volunteer services reduce caregiver stress and strengthen family supports; and 3) the training or skills needed to improve volunteer services targeted to family caregivers.

4. Respite Care Act of 1986

The Respite Care Act of 1986 establishes a statewide respite care demonstration to test the efficacy of providing short-term and extended respite to families caring for disabled elders. This demonstration, to be administered by a state health department, gives priority to Medicaid recipients but offers services to other families on a sliding scale basis.

5. Human Services Reauthorization Act of 1986

The Human Services Reauthorization Act of 1986 reauthorizes the Dependent Care Planning and

Development Grant Program. While 60 percent of the funds are to be used for child care services for school-age children, the remainder of the funds are to be used to establish or expand local resource and referral systems to provide information on dependent care services. Services for the elderly and their caregivers are included in this category.

6. The Alzheimer's Disease and Related Disorders Research Act of 1986

The Alzheimer's Disease and Related Disorders Research Act of 1986, recently signed into law by the President, is designed to coordinate the research, demonstration and evaluation activities of the National Institute on Aging, the National Institute on Mental Health, the National Center for Health Services Research and Technology Assessment, and the Health Care Financing Administration. Among its provisions, this bill requires these agencies 1) to estimate the costs borne by Alzheimer's disease victims and their families; 2) to ascertain the best combination of informal and formal services; 3) to evaluate ways to sustain family caregivers in order to reduce the psychological, social and physical burdens of caregiving; and 4) to identify the best methods of delivering outreach, case management, home care and respite services.

7. Protection and Advocacy for Mentally Ill Individuals Act of 1986

This law requires the Secretary of the Department of Health and Human Services to promote family support groups designed to provide educational, emotional, and practical support to individuals caring for relatives with Alzheimer's or related diseases. These programs are to be established through the National Institute of Mental Health, the National Institutes of Health and the Administration on Aging.

Private Sector Response to Caregiving

Private corporations have begun to express concern about the conflicts experienced by the family caregiver who must simultaneously juggle her/his employment and elder care responsibilities. One observer has suggested that "Company support for elder care is likely to become the new pioneering benefit of the 1990's. It will probably happen faster than the corporate response to child care because it is a more acceptable topic. Women particularly are loathe to admit it when a sick child is the reason for their lateness or absence from work; it could hurt their careers. As one corporate manager put it, 'Eldercare is less toxic than child care. Employees may be more vocal and demand solutions from their employers' " (Friedman, 1986: 51).

This view of employer concern for family caregiving may be somewhat optimistic. In fact, a recent New York Business Group on Health survey (Warshaw et al., 1985) of approximately 70 New York corporations, found that while over half of the companies are aware of employees with caregiving problems, only 15 percent report having policies or programs in place to assist working caregivers. Companies with 2,500 or more employees, an annual gross volume of $10 million or more and a predominately young, female workforce are more likely to have implemented such policies or programs.

Education and Training

By far the most common strategy involves the development of information, education and training programs, viewed as a relatively inexpensive way to assist family caregivers. The Caregivers' Workplace Project, sponsored by the American Association of Retired Persons, is designing a series of training modules which will be made available to the business community to help working caregivers understand the aging process, negotiate the maze of community and institutional services and cope with the responsibilities of elder care. Also, a care management guide is being produced for use by employee counselors.

The Travelers Companies, which has been a leader in the movement toward corporate responsibility for the family caregiver, recently conducted its first caregiver

education fair for its home office employees. Approximately 700 caregivers attended this event to gather information about the aging process, the problems of caregiving and the logistics of dealing with formal care organizations.

Several employers have contracted with local agencies to provide education and training in the area of family caregiving. For example, Pathfinders, a service agency in Scarsdale, New York, is conducting seminars on aging and service delivery issues targeted to caregivers employed with Con Edison, Ciba-Geigy and Mobil Corporation. Similarly, Somerville-Cambridge Elder Services, Inc. offers an educational workshop series called Elderlink to employees of several major companies in Massachusetts.

Respite Care

A few employers are exploring strategies for sharing the costs of purchasing respite care. The University of Bridgeport's Center for the Study on Aging recently initiated the Corporate Eldercare Project in cooperation with four local firms: Remington, Pitney Bowes, People's Bank of Bridgeport and Pepperidge Farm. This project will test the efficacy of several caregiver support models including a telephone hot line to the Center on Aging, work site support groups and a cost-sharing respite care benefit. Wang Laboratories, which already has an on-site child care center, is collaborating with Elder Services in Merrimack Valley, Massachusetts, to explore the feasibility of work-sponsored adult day care. Twenty elderly parents of employed caregivers will be selected for enrollment in one of the local adult day care centers; a one-year follow-up will be conducted to assess changes in caregiver stress, well-being and work productivity.

Employee Benefit Programs

Most companies do not consider the provision of financial support a corporate responsibility. At a time when corporations are attempting to cut costs, such a strategy is seen as prohibitively expensive. Here the public/private partnership has been crucial. More specifically, the Federal government has provided incentives which make it economically viable for

corporations to offer benefits.

One example of such benefits is the Dependent Care Assistance Plan (DCAP) which, under section 129 of the Internal Revenue Code, excludes the value of employer-provided dependent care from an employee's gross income. At the same time, the cost of the care is a deductible business expense for the employer. The program does not have to be funded by an employer; rather, it may be one component of a cafeteria plan for benefits that are funded entirely through voluntary salary reduction by employees (Meeker and Campbell, 1986). Typically, the employee is given a choice between a certain portion of her/his salary and one or more non-taxable benefits. The employee elects the amount of salary reduction and allocates this chosen amount to specific benefits. For example, an employee with a $20,000 salary might reduce the amount by $2,000 and use this non-taxable portion to pay for dependent care services.

According to a recent Conference Board Survey (Friedman, 1986), an estimated 1,000 employers offer a DCAP in a flexible benefits plan. A small fraction of the employees in surveyed companies use the DCAP for child care and none report using it for elder care. The major reason cited for this lack of participation is the requirement that, for tax purposes, the elder must be a dependent of the employee.

The Family and Medical Leave Act of 1986, introduced in the 99th Congress, contains a provision designed to address the concerns of employed caregivers who need to rearrange their work schedules in order to meet their elder care responsibilities. It would require employers of 15 or more workers to allow as much as 13 weeks of unpaid leave for the care of a dependent parent. During the leave period, health benefits would be continued with employees contributing the same portion of premiums as when they are working. Upon return from leave, employees would be guaranteed employment in the same or similar position. The right to this benefit would vest after three months of service, and employees could take such leave every two years.

There has been much controversy surrounding this elder care provision. The U.S. Chamber of Commerce argues that the unpaid leave provision would bankrupt employers and that such decisions should be negotiated on

an individual basis between management and employees. Proponents of the bill see this proposal as a preliminary step toward paid-leave policies which are currently available for child care in many other countries. Others point to the fact that the bill excludes working persons who provide support to a dependent spouse. While the debate will persist into the next Congress, it is clear that employers and employees must develop strategies which enable working caregivers to meet their elder care responsibilities without jeopardizing their job performance and productivity.

V. SUMMARY

This report has provided a comprehensive overview of informal caregiving to the frail elderly. Recent empirical research indicates that family members, friends and neighbors have continued their long tradition as the principal source of long-term care assistance to impaired elderly persons. According to one prominent researcher in the area of family caregiving, "The family, virtually unnoticed, had invented long-term care well before the phrase was articulated. The family made the shift from episodic, short-term acute care sooner and more flexibly, willingly, and effectively than professionals and the bureaucracy" (Brody, 1985: 21).

Nevertheless, the aging of the population, the changing family structure, and the increased labor force participation of women, in conjunction with the increased demand for and cost of community care, have created greater pressures for caregivers than, perhaps, at any time in the past. Even though caregivers are often caught between competing demands, most care is offered willingly and is a source of satisfaction.

National estimates from the 1982 Long-Term Care Survey substantiate the often reported observation that informal caregivers are predominately female. One-third of the caregivers are over age 65, indicating that the informal care system is composed, in part, of the "young-old" caring for the "old-old." Furthermore, caregivers may represent a vulnerable population since one-third are poor or near-poor and one-third perceive their health as fair to poor.

The caregiver is the crucial link in assuring that dependent older persons remain in the community. Indeed, the characteristics of the caregiver, more than those of the care recipient, are essential in predicting the propensity for institutional placement. In general, caregivers only ask for assistance when the responsibility of elder care becomes too difficult. More often than not, the request is for respite services rather than for financial help. And where formal services are used, little evidence has been found to substantiate the concern that caregivers will substitute formal services for their care. Thus, the fear expressed by many that families will "come out of the woodwork" if services are available is largely unfounded.

Today, the average woman will spend 17 years of her life caring for a dependent child and 18 years helping her dependent parent.

Both the public and the private sector have made efforts to address the needs of the caregiver. The public response has focused primarily on legislation to provide services and financial assistance, with an added emphasis on education and training. The private sector has sought to meet the needs of caregivers principally through education and, in some cases, by experimenting with cost sharing for respite care and the establishment of employee benefits.

Caregivers are central to the current long-term care system and will continue to be essential in providing care to our dependent elderly. Caregiving remains one of the challenges of the future.

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